A Voice Beyond Our Numbers: New PH Legislation Provides a Powerful Tool for Change

We all have the right to ask our government to help us solve problems that none of us can solve alone.

~ Steve White, PHA Board Member, after a visit to Capitol Hill

The Tom Lantos Pulmonary Hypertension Research and Education Act of 2011, named for the late Congressman and PH champion Tom Lantos, was introduced this year by Reps. Kevin Brady (R-TX) and Lois Capps (D-CA) and Sen. Bob Casey (D-PA). The bill keeps Congress, the Centers for Disease Control (CDC) and the National Institutes of Health (NIH) talking about PH. It calls for:

- Research through the NIH to help improve PH diagnosis and ultimately find a cure;
- CDC programs to make medical professionals and the general public more aware of PH and help end misdiagnosis.

For the PH community, a bill in Congress is a tool for change. There may be only 20,000-30,000 diagnosed patients in the U.S., but when we educate our senators and representatives and ask them to co-sponsor the Tom Lantos PH Research and Education Act, we have an impact beyond our numbers.

Past advocacy by the PH community has led to new Centers of Excellence in PH, new PH research at the NIH, and new PH-awareness initiatives for patients and medical professionals. We’ve come a long way. The new PH Research and Education Act of 2011 can take us even further.
Do what you can, with what you have, where you are.
~ Theodore Roosevelt

As you can see from the front-page story in this issue, the Tom Lantos PH Research and Education Act was recently introduced in both the Senate (S. 775) and the House of Representatives (H.R. 1810)! This act is essential to furthering our mission because:

1. It is the only PH-specific bill in Congress;
2. It is focused on education for medical professionals and the public with the intent to end misdiagnosis; and
3. It encourages increased funding for PH research at the National Institutes of Health (NIH) in order to improve PH treatment and to find a cure.

On May 20, while I was formulating some ideas for this letter, my daughter’s first grade class had the amazing opportunity to visit the Long Beach Police Department and spend time with the chief. (At this point you are wondering, “How does this relate to pulmonary hypertension?” Please bear with me!) The chief delivered an inspiring message to wide-eyed 6- and 7-year-olds about how success in life is determined by one’s ability to face challenges “head on … and then to pick oneself up and dust oneself off” after experiencing disappointment. He shared highlights from his own life’s journey, which entailed overcoming various formidable obstacles ultimately to take the reins of an extremely vital and complex peacekeeping unit.

While sitting in the chief’s office, I thought about how this important life lesson applies to the PH journey and our newly introduced PH Research and Education Act.

Diagnosis with PH is a life-altering, often overwhelming collection of challenges all rolled into one. After diagnosis, it is understandably difficult to think in terms of dusting off and moving ahead, but many who are affected by PH have discovered that finding a way to fight back helps to regain some control. Advocacy is one of those ways.

Rep. Kevin Brady (R-TX) has introduced the Tom Lantos PH Research and Education Act in Congress every two years since 2000. Over the last decade, through our collective advocacy and conversations with Members of Congress about the bill, we have changed the landscape of PH research. Specifically, these efforts have led the NIH to more than triple its annual investment in PH, and have resulted in the Centers for Disease Control and Prevention funding PH awareness and patient-serving programs through PHA. Together we have made a difference, and I think it has become clear to Members of Congress that we will not quit until this bill passes!

With your help, we have an unprecedented opportunity to accomplish our goal during this Congressional session! If advocacy is not an area in which you have been involved, I would like to encourage you to read the cover article and its related articles on pages 25-27 to learn how PHA makes it easy for you to communicate the difference that this bill will make in your life and the lives of those who have yet to be diagnosed with PH. Your personal story alone has the power to gain support from your Congressional Members, and together our collection of stories makes us unstoppable!

As you leaf through the pages of this edition of Pathlight, you will find countless examples of how members of our community have done what they could, with what they have, where they are! You are undoubtedly one of these involved members, and it is with deep gratitude and admiration that I ask you to do yet one more thing for our cause.

In partnership,

Laura Hoyt D’Anna, DrPH

MESSAGE FROM PHA’S BOARD CHAIR

www.PHAssociation.org      PATHLIGHT SUMMER 2011
For patients with more than one chronic illness, a coordinated health plan and a coordinated health team are key to positive outcomes. As a person with pulmonary arterial hypertension and congenital heart disease, I deal with the delicate balancing act of coordinating different medical teams continuously. This past spring, I had the privilege of interviewing congenital heart disease specialist, Dr. Alison Meadows, about coordinating care among specialists.

As the director of the Adult Congenital Heart Program for Northern California Kaiser Permanente, she deals with a variety of congenital heart patients every day, many of whom are living with multiple chronic diseases such as PH, liver disease, etc. Here she answers some of my questions about how to figure out just who’s responsible for what.

What can I do to facilitate communication among my specialists between appointments?

It is very important for patients who have chronic diseases to have their doctors communicate with each other. More importantly, it is very important for the patient to facilitate this if it is not already happening. If your doctors are not communicating and sharing information, ask them to do so. Make sure that all the doctors have all the records from your tests, follow-up letters, second-opinion letters and notes from the doctors who are part of your care. Be sure that you are active in your care and medical decisionmaking.

What should I do if two of my doctors disagree about a course of treatment?

It is important to find out why they disagree. Some disagreements are simply differences in style; some are based on provider experience. Often there are no right or wrong answers. Importantly, the patient must be comfortable with the ultimate decision. Patients should seek a second opinion if they are not sure how to proceed. If the doctor is not comfortable with this, then that doctor is probably not the right provider for them. Patients have to go with the doctors that they trust.

When I get a cold, a fever, or other “red flag” symptoms, whom should I call and in what order?

In many cases, your primary care provider (PCP) is a good doctor to make decisions about your care and help decide whether or not you should call one of your specialists. If you are clearly having a symptom that is related to one of your chronic illnesses, call the appropriate specialist directly.

I have so many doctors! Do I really need a primary care physician on top of all my specialists?

Yes. The main purpose of a PCP is coordination of care and prevention. This doctor’s job is to stay on top of “the rest of you” and do routine screening. They will keep you on track to get your colonoscopy, mammogram, lipid panel, etc. Seeing your PCP is a preventive measure to keep the rest of your body healthy. Patients with chronic diseases need to remember that they, too, are aging. General health issues will affect them as well. People with chronic diseases are now living longer and are acquiring the “normal” types of diseases and conditions that come with aging. The PCP can also deal with other issues that can affect the patients’ health and well-being such as stress, anxiety and depression.

I have a different specialist to treat each of the diseases that I’m living with. But isn’t it possible my diseases are interacting? Whom do I ask about this?

Yes, all organ systems interact. This is why you need to have coordinated medical care. You need to continually challenge your providers to look at you as a whole person. This is also why it’s important for you to have one central coordinator and decision-maker. This person can be a specialist or your PCP. Whoever this person is has to be willing and interested in taking the lead.

By Melinda Schissel, PH Patient

To share your strategies for coordinating care among specialists, join PH Plus, PHA’s email group for patients with associated diseases. Visit www.PHAssociation.org/EmailGroups#PHPlus
**U.S. Air Force Flies Mission in Honor of PH Patient**

This spring, Kari Trapp, 31, from Rapid City, S.D., taught hundreds of Americans serving in Afghanistan about pulmonary hypertension without ever leaving home. After being nominated by her neighbor, Kari was honored in a U.S. Air Force ceremony on April 16, for embodying courage and strength following her PH diagnosis in August 2010. In the ceremony, airmen flew an American flag on a B-1B Lancer bomber on a mission over Afghanistan in honor of Kari. Kari says, “I just think it’s amazing that hundreds of Americans on the other side of the world have heard about the daily battle of life with PH, and that they’re praying for us and cheering us on.”

In the year following her diagnosis, Kari struggled with the changes she had to make to accommodate her symptoms and complex medication regimen. As a registered nurse and mother of three, she had been accustomed to working 12-hour shifts and chasing after her children, but her PH forced her to adapt to a less active lifestyle. Kari found these adjustments particularly challenging because she felt so alone. She says, “Where I live in South Dakota, people don’t know about pulmonary hypertension. I haven’t met a single person my age who’s battling the same thing. This ceremony showed me that people actually care.”

Michael Mansfield, a 22-year-old airman present at the ceremony, wrote Kari a letter thanking her for being “an inspiration and a role model” to his squadron. Since she was diagnosed with PH as a young adult, Kari said it meant a lot to her that the letter came from someone so young who had already experienced so much. As she explains, “We’re fighting a daily battle with our illness, and he’s fighting his own battle. Everyone’s battling their own thing. And, as PH patients, we deserve some honor, too.”

**What’s Trending in Generation Hope**

**Generation Hope** is PHA’s online community for people living with PH in their late teens, 20s and 30s.

- **On dealing with family members:** “My family sometimes forgets about my condition and calls me lazy. I just remind them that every day is a challenge for me and I may look ‘normal’ but I’m not as I used to be.” ~ Dawn

- **On explaining I.V. lines on first dates:** “It is hard but if he runs, it is about him and not me.” ~ Kathleen

- **On moving back in with your parents after diagnosis:** “I hate feeling like I don’t have as much freedom anymore, especially after living on my own for nine years.” ~ Kit

- **On living life on your own terms:** “We live with enough limitations so my philosophy is that if I CAN do it, if it’s something I love, I’m going to see if I can find a way to do it. Sometimes I might take more time, or go about it in a different way, but most of the time, I get to live my life normally.” ~ Maddy

Join the conversation: [www.PHAssociation.org/GenerationHope](http://www.PHAssociation.org/GenerationHope)
International Faces of PH: Jas Kalra from India

When we asked Jas to share his perspective as a PH caregiver, he said, “I will. Gladly. Anything for PH.” It’s the same feeling that so many spouses of PH patients feel the world over. If your better half is a PH patient, we think you’ll find that you share a lot in common with Jas!

From India, with love

I love the monsoons in Bombay where my wife and I grew up, went to college together, dated, married and had two lovely kids. But on that dark August day last year, the torrent seemed to beat my chest as I stepped outside the doctor’s chamber. In the span of a week, the diagnosis for my wife’s breathlessness had shifted from atrial septal defect to primary pulmonary hypertension. The first reaction was that of disbelief. I went in for second and third opinions, fervently hoping that the doctors would dig out the “hole” that the first echo had erroneously put the cause to. The “no known cause” line stayed and PPH was the new guest at our place.

A few words must be said of the medical system in my country. In about 45 days, we consulted with 13 cardiac/pulmonary specialists at various stages of diagnosis and in different parts of this big country. In my opinion, as a former pharma marketer and doc watcher, 11 seemed capable of a PPH diagnosis in the first visit with appropriate tests made available to them. Of the seven who had seen PPH cases earlier (including a U.S.-based heart/lung transplant surgeon), only five were thoroughly aware of the mainstream allopathic medications available in India. Four of those five had the hope, patience, keenness or control to try out drug combinations over a period of time and test patient responsiveness. Two offered patient “dos” and “don’ts.”

The detection and survival rates for PPH have altered dramatically in the course of the last decade. However, a lot of the information available is gloomy and dated. In India, despite the country being a hub of low-cost pharmaceutical re-engineering, some PH treatments are unavailable due to the small market size. The silver lining, however, is that the traditional herb system (ayurveda), yoga and homeopathy are legitimate in India and have some meaningful cardio-supportive supplements, therapies and food advice to offer.

My biggest challenge as a caregiver has been to put it across to my wife that there is a lot of treatment we can do based on what patients are already doing around the world, mainstream or alternative — the online PH group abounds with tales of courage, ingenuity and survival. Given the quantum of research, the promise of a cure is real. I tell her that I believe we will together grow old, fat and grumpy and that, one day, we will have grandchildren to see.

When times get tough and it feels like relatives, help and luck have deserted us, we have learned to soldier on in a way akin to what the noted poet Tagore prescribed: “If you must, walk alone.”

A final note. Love bonds. It heals. It cures. I see the same glint in my wife’s eyes today that I saw every single day when we dated. The delight in getting lost on a long drive is back, too. Except, now, we always have two noisy and mostly hungry kids in the rear.

Doctor notes from leading heart hospitals in India

Dr. Ravi Kishore, Senior Cardiologist, Narayana Hrudalaya, Bangalore:

The key issue in India is that the diagnostic modalities are restricted to urban centers, hence a vast number of patients remain undiagnosed. There is also a perception among a majority of treating physicians and cardiologists that the diagnosis is a death knell for the patients as there are very limited treatment options available. Newer drugs are expensive. Other drugs, if available, also come at a huge price. And heart-lung transplant may not see the light of the day in the near future.

Dr. Rahul Mehrotra, Consultant Cardiologist, Medanta Heart Institute, Gurgaon (NCR):

The disease is as prevalent in India as in other parts of the world. The management of the disease is demanding for the patient and the caregivers — a key aspect is inclusion of counsel regarding drugs, changes in lifestyle, marriage and family life.

Dr. Geetha Krishnan, Senior Ayurveda Consultant, Medanta Heart Institute, Gurgaon (NCR):

In management of PAH, the general approach one takes is to create “vata anulomanata,” which in simple terms means “channeling the energy.” Panchakarma (purifying) procedures such as vasti, mridu virechanam and pratimarsha nasya are found to offer good support when used judiciously in the course of the disease.

By Jas Kalra, PH Caregiver

Read the full article — with more doctor notes — online at www.PHAssociation.org/PHInternational.
Finding Insurance Coverage During Difficult Times: How One Patient Tapped into Community Resources

My journey with PH began in November 2005. I had just turned 27 and was trying to start a new life with my husband as a newlywed. I was working full time as a case manager for children with special needs. It was a blessing that my employer paid 100 percent of my insurance premium. I still had to pay a $1,000 deductible, but with a diagnosis of PH, that deductible was met almost immediately! Life with PH was good. I had a supportive family and co-workers, great insurance benefits and a rewarding career — what could possibly go wrong?

However, this house of cards tumbled down. On May 20, 2010, (a day I will never forget), I went into work with tears in my eyes. My PH had progressed, and it was very difficult to work a 35-hour week. I had a doctor’s note in my hand stating I was no longer able to work. I went into work knowing I needed to attend an important business meeting. At the meeting we were informed that our employer was having financial difficulties and, as a result, would be cutting half of the staff. I was one of the “lucky” staff, remaining on the payroll but still losing insurance benefits beginning June 1. I gave them my doctor’s note about my worsened condition and informed them I would be applying for short-term disability benefits.

I returned home shell-shocked, not expecting I would be losing all my benefits in an instant. I began to wonder how I, a PHer, could survive without insurance and if it would be possible to get insurance with this pre-existing condition. I immediately went to Maine’s Department of Health and Human Services and applied for MaineCare. Unfortunately, I was denied due to my household assets. (Advice: Don’t buy a timeshare.)

I did a Google search for “health insurance in Maine” and received more than 9 million hits! I tried to sift through the information, but began to notice that the websites were outdated and filled with inaccurate contact information. I didn’t know where to go next. It was so overwhelming, and I didn’t get anywhere. I was without insurance for two months and the bills were racking up.

Finally, I attended a PH support group meeting in July 2010, and when Jeannette Morrill, PH patient and support group leader, asked how I was doing, I unleashed my burdens. Everyone at the meeting said, “Don’t forget about the PHA website; it has a lot of good information.” Liz Mahoney, an Accredo representative, really went out of her way to write down and send me information by mail. She also told me that Caring Voice Coalition (CVC) could possibly provide healthcare premium assistance.

I contacted PHA and spoke to Margaret Beardsworth, the Insurance Program Manager, and she also informed me about CVC and Healthcare.gov. I called CVC and talked to someone, who also sent me information for Healthcare.gov. We reviewed the plans on the website together and discussed the best possible plan for me. CVC then participated in a conference call with my potential insurance provider to address plan questions. Given my budget, the cost for the premiums was crushing and out of my price range; I feared I would not be able to afford it! However, CVC staff reminded me that I could apply for assistance with insurance premiums.

The process for CVC’s application was very easy and the turnaround time was impressive. I was notified that CVC would reimburse $350 toward my premium! After reimbursement, the cost was within my budget. Each month I have to send in a copy of my premium invoice, a copy of my cleared payment and the shipping invoice for my Tracleer™.

My biggest words of advice for all those reading my story is don’t do it alone and don’t wait to make the call for assistance! There are many organizations (like PHA and CVC) that want to help you. You just need to ask.

By Hada Monahan, PH Patient

Contact Margaret Beardsworth, PHA’s Insurance Program Manager, at Margaret@PHAssociation.org or 303-565-3004 x754. Visit www.PHAssociation.org/Patients/Insurance to access PHA’s online insurance resources. Contact the Caring Voice Coalition at CaringVoice.org or 888-267-1440.
Got questions? Get answers.

- **About PH: An Online Guide** – Learn the basics about PH, diagnosis and treatment. [www.PHAssociation.org/Patients/AboutPH](http://www.PHAssociation.org/Patients/AboutPH)

- **Find a PH Specialist** – Look here for a list of PH-treating physicians from around the world. [www.PHAssociation.org/Patients/FindaDoctor](http://www.PHAssociation.org/Patients/FindaDoctor)

- **Pulmonary Hypertension: A Patient’s Survival Guide** – Our comprehensive guide to understanding and coping with PH. Order your copy online at [www.PHAssociation.org/SurvivalGuide](http://www.PHAssociation.org/SurvivalGuide)

- **Tips for Emergencies** – [www.PHAssociation.org/Patients/EmergencySituations](http://www.PHAssociation.org/Patients/EmergencySituations)

- **PHA Classroom** – A place to participate in live e-learning events or watch recordings on your own time. [www.PHAssociation.org/Classroom](http://www.PHAssociation.org/Classroom)

- **Insurance Guide** – PHA’s insurance guide answers questions about coverage and benefits, including disability, Medicare, Medicaid, Social Security and unemployment. [www.PHAssociation.org/Patients/Insurance](http://www.PHAssociation.org/Patients/Insurance)

- **PHA’s Patient Resources List** – A handy guide to organizations that can offer you legal assistance, financial help, and targeted information. Visit [www.PHAssociation.org/Patients/Resources](http://www.PHAssociation.org/Patients/Resources)

- **Access PHA’s caregiver resources** at [www.PHAssociation.org/Caregivers](http://www.PHAssociation.org/Caregivers)

- **Habla español?** [www.PHAssociation.org/Espanol](http://www.PHAssociation.org/Espanol)

Stay in the loop.

- **PHA News** – This free biweekly email newsletter brings the latest news about PH and PHA to your inbox. [www.PHAssociation.org/PHANews](http://www.PHAssociation.org/PHANews)

- **Pathlight** – PHA’s quarterly print newsletter for members and donors provides medical updates, tips on living with PH, support group news and much more. Visit [www.PHAssociation.org/Pathlight](http://www.PHAssociation.org/Pathlight) for back issues.

Looking to help? We’re looking for you.

- **The 435 Campaign** – Reach out to Members of Congress to advocate for PH research and education. Request information and sample letters at [www.PHAssociation.org/Advocacy](http://www.PHAssociation.org/Advocacy)

- **Our Journeys** – Submit your story online to inspire others and help raise PH awareness. [www.PHAssociation.org/OurJourneys](http://www.PHAssociation.org/OurJourneys)

- **PHAware Campaign** – Contact your local media outlets to spread the word about PH! PHA provides a step-by-step Media Guide, press kits and an email group to help you connect with other media advocates. [www.PHAssociation.org/PHAware](http://www.PHAssociation.org/PHAware)

Connect from home

**Patient-to-Patient Support Line:** 800-748-7274
The Support Line is answered by a group of trained volunteer patients who are there for anyone who needs to talk about pulmonary hypertension.

**Online**
Our discussion boards, email groups and chats help you instantly connect with other patients and family members. [www.PHAssociation.org/ConnectOnline](http://www.PHAssociation.org/ConnectOnline)

- Find a personal patient or caregiver mentor at [www.PHAssociation.org/Mentors](http://www.PHAssociation.org/Mentors)

Connect face-to-face

**Support Groups**
Join one of our 230+ support groups nationwide to connect with people who understand what it’s like to live with PH. Find support groups in your area at [www.PHAssociation.org/LocalSupportGroups](http://www.PHAssociation.org/LocalSupportGroups)

**Conference and Patient Education Programs**
PHA’s International Conference brings together more than 1,000 patients, caregivers, medical professionals and other friends of PHA every two years to share information on the latest research, treatments and coping with PH. To learn more, visit [www.PHAssociation.org/Conference](http://www.PHAssociation.org/Conference)

PHA also hosts regional patient education conferences throughout the year. Learn more at [www.PHAssociation.org/OntheRoad](http://www.PHAssociation.org/OntheRoad)

**Special Events and More!**
Attend an event near you to meet patients and support PHA: [www.PHAssociation.org/Events](http://www.PHAssociation.org/Events)

Join our community of hope

Become a member to receive Pathlight, a discount on *Pulmonary Hypertension: A Patient’s Survival Guide* and much more. Visit [www.PHAssociation.org/Join](http://www.PHAssociation.org/Join)
Before my daughter was born, I loved to read. When she was 7 months old, she began to experience some medical issues. Like many parents, I became a consumer of “medical literature” — reading everything. I wanted to find that one tidbit that would make “the difference.” When she was 13 years old, we added a diagnosis of “pulmonary hypertension” to our vocabulary.

My husband and I were overwhelmed, frightened, angry, worried and grieving. How could something so terrible have happened? Her earlier diagnoses were problematic — uncontrolled epilepsy and a developmental delay — but this was different. Even though we had the support of our parents and a few close friends, we felt very isolated and alone and weren’t quite sure how to process it all. We found PHA’s website shortly after diagnosis, but that was little comfort at the time when we were struggling to grasp everything involved with our situation. Now, almost four years later, our daughter is stable, which is far more than her doctors expected. We are incredibly grateful, but our lives as parents of a chronically ill child will never be “normal” compared with many others’ lives.

A few months ago, I made a decision to try and reclaim a little of my “pre-child” life. I was browsing through a catalog when I saw a picture and snippet about the book *Chronic Kids, Constant Hope* (Crossway Books & Bibles, 2000). I started to pass over it, but then I saw the subtitle: “Help and Encouragement for Parents of Children with Chronic Conditions.” I was “hooked.” I ordered it.

Two sisters and mothers of chronically-ill children, Elizabeth Hoekstra and Mary Bradford, wrote this together. They have interwoven tales of their own personal experiences with those of other families. They cover a variety of very relevant topics, such as “Releasing Guilt and Blame,” “Educating Yourself” and “When Friends Say Hurtful Things … and They Will.” Their real experiences finally added some “normalcy” to how I feel as a parent — along with PHA’s parents email group and two family weekends at a camp.

To be sure that no one is misled, you should also know that this book is written from a Christian perspective. It includes scriptural references and Biblical comparisons. The authors do not try to evangelize, but offer the perspective of parents who have grown to rely upon faith to aid them in their situations. For me, this was a tremendous comfort when I also read chapters titled “When You’re Mad at God,” “‘Mommy, Why?’ and Other Hard Questions” and “Expecting Joy.”

In the end, this book has become one of my favorites. When we are having a rough day, I’ve pulled it out to re-read a section or chapter. When I’ve been worried, I’ve used it to find appropriate scripture to bolster my spirit. And when my daughter gets a good report, we have been truly happy and able to focus on that and not the “what-ifs” of PH. I hope you find that it is a practical (and uplifting) experience for you as well. ✦

*By Lisa Garnett, Parent of a Child with PH*

---

**Caregiver Shout-Out! Jennifer Grote honors her husband and caregiver Chad Grote.**

I would like to acknowledge my husband of almost eight years, Chad Grote. He is my rock. I always knew he was a special guy, but through the years of me being sick with lupus and then last May with the diagnosis of PH, he has really stepped up. He does so much for me around the house and for our little girl. He is so patient with me and never pushy or angry that I need so much help some days. If he gets angry, it is because he can’t heal me. Thanks for the opportunity to recognize our caregivers because they mean so much to us.

As we go to press, PHA is saddened to learn that Jennifer Grote lost her battle with PH in June.

---

For a chance to express gratitude to a loved one in Pathlight, email submissions to Caregiver@PHAssociation.org.
Caregiver Mentor Spotlight: Laura O’Donnell

Mentors are patients and caregivers from all over the world, standing by to help patients, caregivers and parents through one-on-one, email-based support. Laura O’Donnell is one of those mentors, and she shares a little about herself now.

How long has your family been living with PH?

I have been a PH caregiver for 10 years. My daughter Shannon was diagnosed with PH as a kindergartner, in 2001. Somewhere along the way my husband and I got involved with a support group. Now we run one for other families of children with PH in the Boston area.

Why should someone email a PHA Mentor?

Email me if you are looking for hope. My family’s experiences can make people who are new to all of this start to feel a little better. This is how I show patients and caregivers the love when I talk to them. We point to our daughter and say, “This is how it could be.” My marriage is stronger than it was when our daughter got sick. We used to have fun all the time. Now I’m tired more often, but we’ve found ways to improve our marriage. We have date nights.

When you feel more comfortable with the day-to-day of life with PH, things will get better. We let Shannon be independent. We let her have sleepovers, and we let her go to the mall. Now I know the difference between not having confidence and having the confidence it takes to live your life. You can’t give up just because you’ve heard the words pulmonary hypertension, and PHA Mentors can help you figure that out.

What are some of the most common questions you hear from PH patients and caregivers?

Oh, I hear all sorts of questions. They want to know why this is happening to them. They want to know if they can travel. A lot of families want to know whether PH kids can swim. In response to all these questions, I tell them about my family’s experiences. To the parents, I say, my daughter’s different from your son or daughter. If you’re a patient, I can’t tell you what’s going to happen to you. But I can tell you what I do, what my husband does, what my daughter does to deal with the meds, the doctors, all of it.

What advice do you have for other families living with this disease?

Your quality of life is important. Keep up with your relationships. Keep busy. Go do things. You can’t be afraid to live. Go for a walk; go to the mall; do something. I was paranoid for a little while, and I kept Shannon in a bubble. But eventually we learned what she could do and what she couldn’t do on her own. Eventually, I had to find small ways to let go. That has kept me sane. I go out with my friends and have coffee. I work two nights a week at Build-A-Bear. Everyone needs some degree of independence, financial or otherwise. You can’t do laundry and clean every single day. Whether you’re a patient or a caregiver, don’t let PH take over your life completely. Go find something of your own that you enjoy.

Email Laura at Laura@PHAMentors.org, or connect with another PHA Mentor by gender, age, associated disease or topic of interest at PHA’s website: www.PHAssociation.org/Mentors

Family members and friends, you are not alone.

Email a caregiver mentor for support.

Patient and caregiver mentors are ready to help at www.PHAssociation.org/Mentors
PHA is delighted to introduce you to Brady, Ryan and Connor. Their mothers are part of our team at the PHA office in Silver Spring, Md., and as you can see, our team is growing! 

Meet Brady David Lucadamo
Doreen Lucadamo, PHA’s Director of Meetings and Conference Planning, and her husband Dave welcomed Brady into the world on Sept. 23, 2010. Brady is already a member of the Baltimore Orioles’ and Ravens’ Kids Clubs, and he is an extremely happy baby. “I love every minute of being his mom, even when I don’t get much sleep,” Doreen says.

Doreen sees her work at PHA as a personal mission. As she explains, “The day before Brady was born, my mother, a PH patient, went into the hospital in Florida complaining of pain. She didn’t know if she would live to ever meet her only grandchild. Since then, she has been in and out of both the hospital and hospice and has had the chance to spend quality time with Brady, including a visit right after he was born, a visit at Christmas and another in March.”

Meet Ryan Xavier Thomas
Keisha Thomas, PHA’s Associate Director of Database, her husband John and son Jayden welcomed a second son on March 14, 2011. Ryan’s middle name, Xavier, is from a character in the X-Men comics, and he loves the song “Itsy Bitsy Spider” as sung by his big brother Jayden. It calms him down. Jayden loves being a big brother. “I often have to remind him not to squish Ryan in his enthusiasm,” Keisha says.

Keisha has been with PHA for more than three years. “The people are the thing I love most about PHA — both the staff and the members,” she says. “PHA brings together an amazing group of people who work really hard to beat this disease. Each day is inspiring.”

Congratulations, Doreen, Keisha and Jillian!

Meet Connor Kevin McCabe
Jillian McCabe, PHA’s Associate Director of Development, and her husband Dave welcomed Connor on March 14, 2011. Connor loves going on walks and having lunch at his dad’s restaurant. “You always hear how being a parent changes your life, and it is true,” Jillian says. “I fall more in love with Connor each day.”

Jillian has been with PHA for more than three years. “The people are the thing I love most about PHA — both the staff and the members,” she says. “PHA brings together an amazing group of people who work really hard to beat this disease. Each day is inspiring.”

Online Videos Offer New Patients Education and Hope in Three Minutes or Less
PHA recently launched a series of online educational videos featuring PH patients and medical professionals. These videos provide newly diagnosed patients and family members with a snapshot of what they need to know to take the first steps after diagnosis. Visit PHA’s website to watch videos on the following topics:

- Understanding PH • Diagnosing PH • Finding a PH Medical Team • Treating PH • Lessons from a Long-term Survivor • Living with PH in your 20s and 30s

Find these videos and more at www.PHAssociation.org/Patients/NewlyDiagnosed
First published in 1998, *Pulmonary Hypertension: A Patient’s Survival Guide* is the brainchild of author Gail Boyer Hayes, a writer and PH patient who has lived with the disease for more than 25 years. As a patient looking for answers about research, treatment and how to make day-to-day life easier with PH, Gail found that there were no patient-friendly resources that addressed her needs — just complicated medical texts. So she put her personal talents to use and wrote the book herself. With the assistance of Dr. Bruce Brundage, Gail’s untried research and writing efforts produced the first three complete editions of the book, providing information, answers, comfort and hope to her fellow members of the PH community.

As the scope of keeping the *Survival Guide* up-to-date grew (thanks to the rapid advancement of the medical understanding of PH), Gail called in reinforcements to help maintain the guide as a relevant and accurate resource for PH patients in the United States and around the world. Under the guidance of Dr. Ron Oudiz, the *Survival Guide*’s medical editor, this resource is now updated annually by a volunteer writing and reviewing team of more than 25 patients, caregivers and medical professionals. The book that first grew out of one patient’s need continues to be a valued resource, thanks to the time and expertise of a dedicated team of PH community volunteers.

The *Survival Guide* team’s most recent efforts are debuting this summer in the form of the fourth edition of the *Survival Guide*. In addition to a totally redesigned cover and interior, the fourth edition features a new chapter called “Caregiving” and five updated chapters including: “How Do I Know I’ve Really Got PH,” “PH Drugs,” “Surgical Treatments,” “Children and PH,” and “Tedious Paperwork and Legal Matters.” To purchase your copy, visit [www.PHAssociation.org/OrderSurvivalGuide](http://www.PHAssociation.org/OrderSurvivalGuide) or call 301-565-3004.

Thank you to all the patients, caregivers and medical professionals who assisted with the publication of the fourth edition of the *Survival Guide*!

**PHA Board of Trustees Welcomes Two New Members**

PHA welcomes two new members to our Board of Trustees. The Board serves in a governance and oversight capacity, ensuring that PHA’s programs meet the needs of all our constituencies. Visit [www.PHAssociation.org/BoardOfTrustees](http://www.PHAssociation.org/BoardOfTrustees) to meet all Board members.

Colleen Brunetti, Generation Hope Advisory Board Member, Online College Instructor and Owner of “Little Hands, Big Ideas”

Colleen was diagnosed with PH in 2008 shortly after the birth of her son. Since then she has become incredibly involved in the young adult patient community. She joined the Generation Hope Advisory Board and takes part in welcoming new members to the group, as well as exchanging ideas and information. She also recently wrote a *Pathlight* article (Spring 2011), “Helping Your Child Cope with Your Illness,” as a resource for other parents dealing with the disease.

Diane Ramirez, Advocacy Chair, North Carolina Support Group

Diane joins PHA’s Board as a long-term PH survivor, having lived with the disease for more than 20 years. At the time of her diagnosis, no treatments existed. Instead of giving up hope, Diane decided to raise awareness of the disease by talking to the media. Over the years, she has spoken to news stations, representatives in the House and Senate and most recently the *New York Times*. She also encourages her North Carolina Support Group to promote awareness of PH.
Is there anything higher on a PH patient’s DISLIKE list than the dreaded right-heart catheterization? I know it’s my least favorite. My brother John hates them, too. John was diagnosed with pulmonary hypertension in 1995, and I was diagnosed in 1998. Our mom lost her sister Josie to PH in 1963, so we have the genetic thing going in our family. I’ve lost count now but, counting the marks on my neck, I think I’m up to 12 or 13 catheterizations and John’s had his fair share, too. Since we were both due for a catheterization, I suggested we go together. I figured we could share the long ride from Long Island, N.Y., into Manhattan, and our spouses could keep each other company while we were doing our thing.

We got to the hospital and made our way up to the catheterization lab. I had to have an echocardiogram done first (John had his done the week before), so big brother settled in and got on the schedule first. Dam it! I wanted to go first! After the echo, I waited outside the lab for someone to come and get me when I got my first text message from him. It read, “Be brave today. Don’t cry. Preserve the family’s good name!” Nice. You see, my fellow PHers, in those first few years after diagnosis, I used to cry through the whole catheterization. I’m sure it was a nervous reaction/tension reliever/stress thing. The doctor also had a very hard time getting my arterial line in, so I cried a lot, but that was more than 10 years ago. I texted him back with a sharp retort that cannot be repeated here and gave him a suggestion to keep himself busy. I also told him I hadn’t cried in years.

One of the wonderful staff members of New York Presbyterian Cardiac Catheterization Laboratory came to get me and settled me into a cubicle with a door and everything. Ha! Victory! My brother was in a curtained off area two sections away. After I changed into my high-fashion hospital gown, I made sure to saunter over to his vicinity to gloat about my superior accommodations. Score one point for the little sister. When the nurses came to get my intravenous therapy going, I chatted them up.

“Listen,” I told them, “that’s my brother John in the curtain two area, and he is in desperate need of a prostate exam. Can we get that ordered for him right away?” They giggled, but told me they couldn’t address that request in the catheterization lab. Drat.

Big brother got to go in first and smiled broadly as they wheeled him past my door. I wished him luck and told him to enjoy himself. I settled in for the wait and tried to lay back and enjoy the relaxer pill I was given. Yes, even after 12 years of PH and 13 catheterizations, it’s still a nerve-wracking experience, but we know what to expect and we hope for the best. I said a little prayer that John’s catheterization would go well and we’d hear good news about his numbers.

He was done fairly quickly, but of course our fun and games were far from over. By this time, I was feeling very dreamy (thank you, Valium) and relaxed. “Here comes your bro,” my husband told me. As they wheeled John past my door, he decided to pantomime a seizure of sorts. His performance was brilliant, complete with drooling, shaking and nonsensical babbling. He had the nurses laughing. “Very funny, John! Hilarious!” I called out. “Don’t shame the family,” he replied. I tried one more time to get the nurses to give John that much-needed prostate exam, but they weren’t buying it.

Thankfully, my catheterization went great and we both got good news on our pressures. We decided to celebrate and hit our favorite restaurant for dinner on the way home. Yes, brother and sister: our relationship will always be one based on nuggies, merciless teasing and fun childhood memories. In all seriousness, I know that I’m incredibly lucky to have my brother. He went through everything first and has prepared me for all the ups and downs of being a PH patient. We compare notes all the time and support each other through this journey called pulmonary hypertension. He’s the best.

So the next time you’re getting cathed, I recommend bringing a friend (or a relative). By the way, did I mention that John is 50 and I’m 46? Bet you thought we were a lot younger.
It sounds funny to say a gall bladder attack saved my life, but it’s true. Had it not been for gall bladder trouble in late April last year I would not have found out that pulmonary hypertension — compounded by scleroderma in my lungs — was the condition that was making me short of breath and potentially cutting short my life.

My doctors tell me this had probably been developing for a number of years. It was so gradual that I really didn’t notice it; like many undiagnosed PH patients I had attributed my fatigue and difficulty breathing to getting older and being overweight.

In any case, it became clear during the winter and spring of 2010 that something very wrong was happening in my heart and lungs. I was unable to climb even a single flight of stairs without stopping to catch my breath.

Because of this, I had made an appointment with my regular doctor to find out what was going wrong, but fate interrupted what would have likely been months of medical tests and visits to various specialists before coming up with an answer.

Although I’d never had trouble with it before, I suddenly began showing symptoms of a gall bladder attack in late April. This coincided with the doctor’s appointment I had already made, and he determined I needed surgery to remove it the next day.

During the surgery the oxygen level in my blood and my blood pressure both suddenly dropped dangerously low. The surgery was stopped immediately, and I was airlifted to St. Joseph Mercy Hospital in Ann Arbor, where I spent more than a week in the intensive care unit.

That first night was the worst. I was in a coma, and doctors told my wife they weren’t sure I would make it until the morning. I made a remarkable turnaround in the middle of the night, however, and I fought hard to do what was needed to leave the hospital as soon as possible.

That turned out to be days ahead of when the doctors thought, and I was sent home after being set up with oxygen 24 hours a day and a fistful of appointments for pulmonary specialists and tests.

Dr. Kristine Phillips, a rheumatologist at Ann Arbor’s University of Michigan Hospital, diagnosed the scleroderma in my lungs, and one of the pulmonary doctors finally suggested PH as a diagnosis and sent me to Dr. Vallerie McLaughlin, a world-renowned PH specialist at U of M. A right-heart catheterization and a six-minute walk test at the beginning of August confirmed the diagnosis.

It was difficult to make peace with being told that my condition was incurable, and that while the damage to my heart from PH was reversible, the damage to my lungs from the scleroderma was not. Over the past year I have had plenty of time to think about the phrase, “life-changing disease.”

By all accounts I have responded well to my treatments, but it certainly seems like it has been a long road to get to this point. As a result of my doctors putting me on permanent disability, I’ve been away from my job as a newspaper editor for more than a year. I’ve had to watch out the window while my wife and elderly in-laws do all the work in the yard and garden that were once my domain. I’ve had to carefully choreograph simple things like a trip to the grocery store.

On the other hand, I also know I have made great progress and have come to realize that the things I have lost certainly don’t compare to the many things I still have. Like all chronic disease sufferers, I have good days and bad days, but I’m thrilled to say the bad days are now few and far between. A year ago I was pretty much stuck in a chair, watching TV and waiting for my next doctor appointment or medical test — and worse, wondering why this happened to me.

Now I’m able to drive, run quick errands, make short shopping trips, do light housework, resume cooking and baking, and even get out in the garden for short periods. This may not sound like much, but it helps me feel more “normal” and less like a liability or burden to those around me. I simply have to be careful not to do too much in one day, and learning what my new limits are has been an adventure.

This has also reminded me to be more grateful for the new perspective on life that I’ve developed. I’m grateful to be treated by a world-class team of doctors who are only 40 miles from my home; I’m grateful that my only real “handicap” is an inability to breathe normally; and I’m forever grateful for the love and prayers of my friends and family. I’m certain that I couldn’t have made it this far without them.
Q: What is the connection between sleep apnea and PH?

A: Obstructive sleep apnea (OSA) has been identified as a significant cause of and/or contributor to cardiovascular disease. OSA has been shown to increase the risk for hypertension, pulmonary vascular disease, ischemic heart disease, stroke, congestive heart failure, and arrhythmias. The true relationship remains controversial despite the growing body of evidence that links OSA to the development of cardiovascular disease. Many risk factors for OSA are also known risk factors for cardiovascular disease, such as age, male gender, obesity, diabetes mellitus and hypertension. Therefore, it is difficult to prove whether OSA independently causes cardiovascular disease.

Effect of Sleep-Disordered Breathing on Body

Episodes of sleep-disordered breathing cause blood vessel changes that can cause and contribute to cardiovascular disease. The adverse effects that OSA imposes on cardiovascular function are thought to arise from recurrent cycles of not breathing, intermittent hypoxia and the resulting arousals. This cycle of nocturnal desaturation results in an increase in sympathetic tone, impaired nitric oxide synthesis, endothelial dysfunction and ultimately leads to vascular and cardiac dysfunction, atherosclerosis and hypertension.

Pulmonary Hypertension

The 2004 American College of Chest Physicians (ACCP) consensus panel found that pulmonary hypertension occurred in 17 percent to 53 percent of individuals with OSA, whereas a review from Johns Hopkins found that 82 percent of patients with pulmonary arterial hypertension had underlying sleep-disordered breathing. The nocturnal drop in oxygen impairs nitric oxide synthesis and causes vascular remodeling which can lead to the development of pulmonary vascular disease. However, whether OSA independently causes clinically significant pulmonary hypertension remains controversial. Thus, the current ACCP guidelines do not recommend evaluating patients with OSA for pulmonary hypertension unless it is clinically suspected. However, patients with pulmonary arterial hypertension should be evaluated for OSA.

Treatment

CPAP (continuous positive airway pressure) has been shown to be effective in patients with heart failure. Controlled trials have shown that treatment of OSA with CPAP is associated with significant improvements in cardiac function, sympathetic activity and quality of life. In the Canadian Positive Airway Pressure study, CPAP improved nocturnal oxygenation, increased left ventricular function, lowered norepinephrine levels and improved functional capacity among patients with sleep apnea and heart failure. Several recent studies have shown reductions in pulmonary artery pressure in patients with OSA after nocturnal CPAP treatment.

Answer provided by David Pham, MD, FCCP, Pulmonary Hypertension Specialist, Pulmonary & Critical Care, Lung Care Center, Fountain Valley, Calif.
Top Five Reasons for Allied Health Professionals to Attend the 2011 PH Professional Network Symposium

1. **Continuing Education Sessions**
   The 2011 PH Professional Network Symposium Inspiring Hope: New Directions in PAH boasts nearly 30 educational sessions for allied health professionals with the opportunity to receive a maximum of 11.25 contact hours of CE/CME credit! New educational programming for 2011 includes a virtual catheterization presentation, expanded pediatric programming and sessions for pharmacists.

   “The Symposium was rejuvenating and inspiring. The sessions were literature-based but also focused on ‘real world’ applications, addressing the hurdles we face as PH practitioners on a daily basis.”
   ~ Jennifer Priziola, PharmD, BCPS, William Beaumont Hospital

2. **Networking with Colleagues — Plenty of It!**
   Symposium will give attendees ample time to network with fellow PH medical professionals, including planned networking receptions, the “Who’s Who?” contact book and the PH Professional Network (PHPN) Mentor program.

   “The Symposium gave me the opportunity to network with PH professionals from all over the country. Sharing stories, experiences and ideas was inspiring, energizing and fun! I’ve remained in contact with colleagues who I feel are not only great resources but friends!”
   ~ Frances Rogers, CRNP, Hospital of the University of Pennsylvania

3. **Advocacy for PH on Capitol Hill**
   The Symposium offers allied health professionals the unique opportunity to meet face-to-face with Members of Congress and educate them about pulmonary hypertension and the Tom Lantos Pulmonary Hypertension Research and Education Act of 2011. Learn more on p. 16

4. **Updates on Research — from Peers!**
   Attendees can learn about the new research their colleagues are working on in the field of PH at the 2011 PH Professional Network Symposium Poster Hall. Interested medical professionals can present their own research for display and highlight the work their institution is doing!

   “The PHPN Symposium has given my nurses the chance to present at a professional meeting without the stress of giving a ‘talk.’ It is a great chance to network with peers, and I hope all attendees consider submitting an abstract!”
   ~ Laura Savage, RN, MSN, PCCN, VCU Health System

5. **FREE Registration!**
   The 2011 PH Professional Network Symposium offers FREE* registration to the first 300 allied health professionals registered. With up to 11.25 CE/CME credits available, this is a great value for any allied health professional! These registrations are reserved on a first come, first served basis so don’t delay — register now.

   *A $50 deposit is required to reserve a space and will be refunded after the Symposium. However, cancellations received after Sept. 16 and “no shows” are not eligible for refunds. In order to receive free registration, attendee must be a paid member of PH Professional Network. Membership in PH Professional Network is $35 annually.

Allied Health Professionals, Represent Your Patients on Capitol Hill!

Legislative staff seldom get visits from medical professionals who are there to represent their patients. **The PH community is different.**

In September, more than 100 nurses and other allied health professionals from the PH community will visit Capitol Hill to ask their Members of Congress to help find a cure for PH by co-sponsoring the Tom Lantos PH Research and Education Act of 2011.

Please share this information with your PH medical professionals!

---

**PH Professional Network Advocacy Day**

**Thursday, Sept. 22, 2011**

11:00 a.m. — 5:30 p.m.

Training, transportation and box lunch provided

- Make the most of your trip to the D.C. area for the PH Professional Network Symposium by arriving in time for Advocacy Day.
- Share your unique perspective on PH — your own story plus the stories of your patients.
- Provide Members of Congress first-hand information about the many ways your work would benefit from PH research.
- Make your voice heard, support your patients and deliver a critical message on behalf of the entire PH community!

Learn more and register: [www.PHAssociation.org/PHPN/Symposium/AdvocacyDay](http://www.PHAssociation.org/PHPN/Symposium/AdvocacyDay)

---

New Pediatric Courses Available on **PHA Online University**

PHA representatives recently attended the Annual International Neonatal and Childhood Pulmonary Vascular Disease Conference, a conference highlighting the newest advances in the field of pediatric pulmonary hypertension. We recorded many of the sessions, and the recordings are becoming available on a rolling basis for continuing medical education credit on PHA Online University ([www.PHAOnlineUniv.org](http://www.PHAOnlineUniv.org)).

This conference featured a wide array of topics — including transitioning pediatric patients to adult care and examining the genetics of PH — presented by leading clinicians and researchers in the field. These recordings present the most up-to-date information about the etiology and treatment of pulmonary hypertension.

Patients, tell your medical professionals about these important new recordings.

---

Here’s a sampling of the recorded sessions:

- **Introducing Intrapulmonary Arteriovenous Shunt Pathways**, Dr. Marlowe Eldridge, University of Wisconsin School of Medicine and Public Health, Madison, Wis., USA
- **Endothelial Progentior Cells and Chronic Neonatal Pulmonary Hypertension**, Dr. Bernard Thébaud, University of Alberta, Edmonton, Alberta, Canada
- **Evaluation and Diagnosis of Protracted Neonatal and Respiratory Failure and Pulmonary Hypertension**, Dr. Steven Archer, University of Chicago, Chicago, Ill., USA
- **Effects of Elevated FiO2 on Vascular Structure and Reactivity**, Dr. Robin Steinhorn, Northwestern University School of Medicine, Chicago, Ill., USA

Log onto [www.PHAssociation.org](http://www.PHAssociation.org) to view these presentations and more!
Sickle cell disease (SCD) is one of the most common monogenetic inherited disorders worldwide. The disease is caused by a mutation in one of the hemoglobin protein chains that produce an abnormal hemoglobin named hemoglobin S. Hemoglobin S causes red blood cells to become entrapped in small blood vessels as well as break down inside the blood vessels, a process called hemolysis. These abnormal phenomena lead to severe anemia, frequent episodes of pain due to tissue ischemia and injury to vital organs.

Pulmonary complications are major causes of death in patients with SCD. Among these complications, pulmonary hypertension has emerged as a major threat to the well-being of these patients. Over the last five years, we have learned a great deal about the role of PH in SCD, but there are still several questions that remain unanswered about this disorder.

**How common and what is the impact of pulmonary hypertension in sickle cell disease?**

Multiple studies have demonstrated that approximately 30 percent of patients with SCD have an elevated estimated pulmonary artery systolic pressure assessed by echocardiogram or abnormal elevations in brain natriuretic peptide levels, a hormone released by the heart ventricles in response to pressure or volume stress. More importantly, patients with these abnormal parameters are five to 10 times more likely to die, suggesting that these biomarkers are useful to identify a group of patients with SCD at a very high risk of death.

It is important to point out that not all patients with an elevated estimated pulmonary artery systolic pressure will have PH. It is estimated that 6 percent to 10 percent of patients with SCD have right heart catheterization-proven PH. Interestingly, when compared to patients with traditional forms of PH (e.g., idiopathic PAH or PAH associated with scleroderma), these patients tend to have mild to moderate elevations in pulmonary pressures but similar impairments in exercise capacity and similar mortality rates.

**What are the causes of pulmonary hypertension in sickle cell disease?**

It is clear that there are several risk factors and etiologies for pulmonary hypertension in patients with SCD. Clinical and laboratory studies suggest that a main mechanism associated with the development of PH in SCD is the presence of hemolysis, which leads to the release of free hemoglobin into plasma which inactivates the vasodilator nitric oxide. This decrease in nitric oxide activity leads to vasoconstriction, vascular proliferation and activation of coagulation pathways in the pulmonary vasculature. Other contributing factors include chronic thromboembolic disease, chronic hypoxia (low oxygen levels), chronic liver disease and relaxation abnormalities of the left ventricle (also known as diastolic dysfunction).

**What are the treatment options for patients with sickle cell disease and pulmonary hypertension?**

Currently, there are limited data on the effects of any specific treatment modality for PH in patients with SCD. One of the first treatment priorities should be to maximize SCD treatment with hydroxyurea or chronic red blood cell transfusions. In patients with proven pulmonary arterial hypertension, treatment with PAH-specific drugs should be considered based on what is known for other diseases associated with PAH. However, there are very little treatment data from studies in patients with SCD.

We have recently conducted a study testing the role of sildenafil in patients with SCD. This placebo-controlled study was designed to test whether sildenafil could improve exercise capacity (assessed by the six-minute walk test) in 132 patients with SCD with an elevated estimated pulmonary artery systolic pressure assessed by echocardiogram and a low six-minute walk test distance. After 74 patients were enrolled, the study was stopped early due to a higher percentage of subjects experiencing serious adverse events in the sildenafil group (45 percent of sildenafil, 22 percent placebo). This difference was due to a higher rate of hospitalizations due to sickle cell-related pain episodes in the sildenafil group (35 percent with sildenafil vs. 14 percent with placebo). Unfortunately, these surprising findings prevented the completion of the study and full analysis of efficacy data.

**Conclusions**

An elevated estimated pulmonary artery systolic pressure assessed by echocardiogram is common in patients with SCD and a major risk factor for death in these patients. Pulmonary hypertension is also common in SCD and is associated with decreased exercise tolerance and an increased risk of death. There are many conditions that can cause PH in SCD. Sildenafil...
PHPN Announces Revitalized Mentor Program

The PH Professional Network (PHPN) announces the newly revitalized PHPN Mentor Program. This program was revamped to meet the growing needs of the PH allied health community and seeks to connect more experienced professionals with those who are newer to the field of pulmonary hypertension.

Mentors are available to answer questions and provide individual support to new PHPN members who express a need for support in the following areas:

- Sharing clinical practice experiences;
- Understanding their role in a collaborative practice;
- Defining their role as an active member of PH Professional Network.

To request a mentor or for more information, contact PHPN@PHAssociation.org

Allied health professionals: Don’t miss the opportunity to learn more about the PHPN Mentor Program at the 2011 PH Professional Network Symposium Inspiring Hope: New Directions in PAH this September, where attendees will be able to network with PHPN mentors and ask questions related to their areas of expertise. For more information about the Symposium, turn to p. 15.

PH Resource Network Changes Name

PH Resource Network recently changed its name to PH Professional Network (PHPN) to better reflect its increasingly diverse membership of nurses, pharmacists, physician assistants, nurse practitioners, respiratory therapists, physical therapists, dietitians and other allied health professionals working in the field of PH. Over the next year, PHA will be transitioning our materials to reflect this change. We are excited about the opportunities this new name will offer as we look to provide further support and targeted resources to the range of disciplines involved in providing care to PH patients.

To learn more about PH Professional Network, visit www.PHAssociation.org/PHPN

Suggested Reading

5. JAMA 296(3):310-8, 2006

By Roberto F. Machado, MD, Associate Professor of Medicine, Section of Pulmonary, Critical Care Medicine, Sleep and Allergy, University of Illinois at Chicago
A PH Patient’s Guide to Summer

It’s that time of year again … time to pull out the shorts and fire up the barbecue! Summer is a time for outdoor fun with family and friends. There are, however, a few things you should remember when you are off to enjoy all this season has to offer.

1. **Take care of your medication.**
   - Many medications are heat and light sensitive. Take care to keep your medications in a cool, dry place. For those patients on continuous infusion medication, be sure to keep your pumps, lines and back-up medications protected from the heat and light. Flolan™/epoprostenol patients need to be sure to pack extra ice packs on especially warm days and keep them cool. Do not leave your medication/ice packs in the car for prolonged periods in the warm weather.
   - Be sure to have all of your medication appropriately labeled. This will be especially helpful in an emergency or when traveling through airport security.

2. **Stay cool.** There are a few reasons to stay in the shade when the sun comes out:
   - Many of the medications given for PH can increase the risk of sunburn. It is important to wear sunscreen with an SPF of at least 15 and to try to avoid prolonged exposure to sunlight.
   - Excessive heat causes dehydration, which can alter your electrolyte balance. Patients on diuretics and potassium replacements need to be extra cautious to avoid dehydration. Be especially careful when consuming caffeinated drinks or beverages containing alcohol.
   - Spending time in the heat can increase your thirst, which can lead to fluid overload, putting stress on your heart.

3. **Pay attention to your dressings.**
   For patients on continuous infusion therapy, keep in mind that sweat can loosen your dressings. Be sure to check them often for lifting. Bring back-up dressing change supplies in case your dressing comes loose.

4. **Watch your salt!**
   Summer can be particularly challenging for PH patients, especially when presented with the enticing high-sodium foods generally served at outdoor cookouts. Remember that salt and water are best friends. The more sodium you consume, the more fluid you will also consume. Too much fluid can worsen your PH. There are plenty of helpful resources to learn how to enjoy the same foods as your friends while still taking care of your PH. The American Heart Association has a section full of low-sodium recipes: [www.PHAssociation.org/HeartLowSodium](http://www.PHAssociation.org/HeartLowSodium). Also, a helpful section on controlling salt and sodium consumption can be found on PHA’s website: [www.PHAssociation.org/SaltAndSodium](http://www.PHAssociation.org/SaltAndSodium). Additionally, many low-sodium cookbooks are available at your local library.

5. **Most importantly: Have fun this season!**

“Deep summer is when laziness finds respectability.”

~ Sam Keen

_By Lisa L. Roessel, FNP-BC, Pulmonary Hypertension Program Coordinator, Legacy Pulmonary Clinic, Portland, Ore._
Meet Dr. Murali Chakinala: A Passionate Ally in the Fight Against PH

Dr. Murali Chakinala is an Associate Professor of Medicine at Washington University School of Medicine in St. Louis, Mo. He is a member of PHA’s Scientific Leadership Council (SLC), the guiding body for PHA’s clinical, research and medical education activities, and he serves as chair of the PHA 30-City Medical Education Program Planning Committee. He also recently served as 2011 PHA on the Road Regional Committee Chair for St. Louis. The following is an interview with Dr. Chakinala.

You specialize in pulmonary and critical care medicine. What initially sparked your interest in PH? I became acquainted with PH in the late 1990s, during my training to become a lung transplant physician at Washington University. At the time, only epoprostenol (Flolan™) was approved, and patients were typically listed for transplant soon after diagnosis. I was captivated by a couple of patients, particularly how they were transformed from being severely debilitated to being active and vibrant again. PH also provided me the opportunity to meld some of favorite subjects from medical school: pulmonology, cardiology and rheumatology. This fascination, coupled with some serendipity, launched my career as a PH specialist. It’s still such a new field with new therapies, evolving treatment strategies, growing timelines and so many unanswered questions that it remains just as captivating 10 years later.

What advances in PH treatment have you seen since you first started practicing? Pretty much everything is an advance! We went from one IV therapy to nine FDA-approved therapies in about 10 years. The biggest things, however, are the push to simpler therapies, widespread use of combination therapy, and the ability to delay and in some cases avoid transplantation altogether. We still have a long way to go, but we should be proud of what we as a community have accomplished.

What is the most important piece of advice you give your PH patients? Be your own advocate! This is a tough disease, and there is a lot of misunderstanding among healthcare practitioners. Don’t assume that all practitioners understand the disease and know what’s best for you. If things aren’t going as advertised, seek additional input, especially at PH Centers across the country. Become educated about your disease and network with others. There is such a rich network around the country, and it’s a shame not to take advantage. There is strength in numbers!

How did you become involved with PHA? I knew from the beginning how vital PHA is to the fight. In 2002 I went to my first eye-opening support group meeting. Later that year, I attended my first PHA International Conference and was awestruck by the entire experience. I have been to every PHA International Conference since then and have proudly served on numerous panels and committees.

As our center matured, I understood the necessity for an active PHA presence in our area. We’re blessed to have wonderful support group leaders in our region who work closely and tirelessly with us to get the word out about PH, educate/empower patients and help ground us as medical professionals (who sometimes can get lost in the numbers). Being invited to serve on the SLC is one of my proudest professional accomplishments, as I am incredibly honored to serve alongside the giants of the PH field. While my time as 30-City chair hasn’t been long, I have already found it to be incredibly rewarding. To me, these positions are merely the latest way I can help PHA, which has helped me, our center and our patients immeasurably over the years.

You also served as the 2011 PHA on the Road Regional Committee Chair for St. Louis. What effect did this experience have on you? First, I was incredibly proud that PHA chose St. Louis as one of the four sites in 2011. It was an affirmation of the efforts of so many folks in our region, including my nurses, our support group leaders, our patients and their loved ones. I thoroughly enjoyed the planning process and was thrilled that we recruited representatives from four other centers in our region. It was a collective effort, just like everything else at PHA!

Anything else you’d like to add? Everyone always says how thankful PHA is for the efforts of the medical community … and it should. But we don’t always give thanks for what PHA and our patients give us. I became a physician to help people, pure and simple. This community has provided me the means to do just that. But beyond that, it provides scientific stimulation, emotional gratification, and a sense of purpose that so many in the world are deprived of. And for that, I’m extremely grateful to my patients, PHA and the community at large.
Join the 50 State Media Challenge:
Get News Coverage in 35 States by Sept. 1!

Since PHA’s 50 State Media Challenge kicked off at the beginning of 2011, PHers have received 36 news articles in 23 states. We’re almost halfway to our goal of raising awareness in all 50 states. Help us get the rest of the way there! Get involved in the challenge and find out how you can get a media success in your state. For tips and resources to get you started, contact Elisabeth Williams at 301-565-3004 x753 or Elisabeth@PHAssociation.org or visit www.PHAssociation.org/Awareness/50StateMediaChallenge

In the meantime, get inspired by a few of the 50 State Media Challenge success stories from across the country:

**Dunne Family Raises PH Awareness in Multiple Newspapers (Delaware)**

Pulmonary hypertension patient Molly Dunne has appeared in several local newspapers in the state of Delaware. For each of the articles, Molly’s family and friends talked to reporters about her PH diagnosis, medical progress and the fundraiser they organized to help cover Molly’s medical costs. “We’ve been lucky to find a real ally in a local reporter who has been kind enough to promote all of our fundraisers,” says Erin Lacy, a family friend. “I recently wore my ‘I believe in Molly’ shirt and had someone stop me and ask if it was Molly Dunne — I was thrilled! It’s exciting to get the word out there and get people educated about PH.”

**Transplant Recipient Educates about Organ Donation (Virginia)**

Maddie Shinaberry was interviewed in the Pittsburgh Post-Gazette last year about her 2009 double lung transplant. Recently, she was interviewed again about her advocacy work promoting organ donation. Maddie speaks to local school classrooms about her lifesaving double lung transplant and is working with Virginia Delegate Richard P. “Dickie” Bell on a bill that would require 30 minutes of organ and tissue donation education in all ninth-grade health classes throughout the state of Virginia. “I want them to know the shocking statistics,” Maddie says. “About how much of a difference you can make.”

**Support Group Leader Reaches out to PH Patients (Missouri)**

Florine Tripp talked with the Columbia Daily Tribune about her life with pulmonary hypertension and her new role as the Mid-Missouri Support Group Leader. Florine encouraged the reporter to reach out to other support group members, her PH doctor and PHA for background information on PH. That left Florine free to focus on telling the reporter about her role as a support group leader and her life with PH. In the article, Amy Fair, a fellow support group member, said, “Even if nobody else shows up [to the support group meeting], I’ve met Florine, and Florine and I are together.”

**Lifelong Friends Talk about Life with PH (California)**

Dawn Contreras and her best friend Amanda Schulte were diagnosed with pulmonary hypertension when they were kids. In an article that appeared in the Modesto Bee, which has more than 175,000 readers, Dawn and Amanda talked about their lifelong friendship, Amanda’s recent transplant surgery and Dawn’s wait for a double lung transplant. “We both know the anticipation,” Amanda says. “We both know the fear.”

“It’s exciting to get the word out there and get people educated about PH.”

Add more stars to our map! Tell your story and help us spread PH awareness to 35 states by Sept. 1.
How many times have you asked yourself, “What can I do to make an impact in the fight against PH?” Whether you are brand-new to our community and ready to get involved or you are an experienced advocate or awareness-raiser, now is the perfect time to rally the financial support of your family and friends through a personal fundraising page.

No one can do it alone. And that’s exactly why PHA offers a program to help your family and friends show you their support while helping to enhance lives and defeat PH. PHA’s Web of Friends program provides the perfect opportunity to share your story and raise awareness of PH while raising funds to support PHA’s programs and services.

People launch a personal fundraising page for a variety of reasons. Some start a page to honor a patient, like Laura D’Anna, who raises research funds in memory of her sister, Rachel; others celebrate a personal milestone, like Dave Rider, a PH patient who started a page in honor of his birthday. Others create a page simply to give back and make a difference in the fight against PH.

Most importantly, online fundraising is for everyone, not just the tech-savvy: if you can send emails, you can start fundraising online for PHA! We have a step-by-step guide on our website and you can contact me for more information or to brainstorm your ideas.

Whether you’re still deciding to do a Web of Friends campaign or are ready to get started, PHA is here to help! For more information or to get started, visit www.PHAssociation.org/Fundraise/Online, email Giving@PHAssociation.org or call Jennifer at 301-565-3004 x756.

By Jennifer Kaminski, PHA Development Associate

Attention Facebook Fanatics

Move beyond Facebook Causes and make Web of Friends your home base for raising funds online. Unlike special Facebook wishes that last only a few weeks, fundraising pages can remain active for years — giving you a better chance to reach your network when they’re able to give. Plus, you can still use your Facebook Wall to promote your page and raise funds for PHA.

Michael McGoon, MD, a PH-treating physician and member of PHA’s Scientific Leadership Council and Board of Trustees, has been inspired by PHA’s work and the stories of its members. “PHA is a unique organization,” Mike says. “From a medical perspective, it’s amazing to see a group of patients, caregivers, researchers, physicians and allied health professionals all working toward a common goal. His wife, Bonnie, has been just as involved.

To read how Mike and Bonnie continue to devote their efforts to defeating PH, visit PHAssociation.org/Give/McGoon

Like the McGoon family, you can strike a blow against PH by designating PHA as a legacy beneficiary. Your contribution will help shape a brighter future for all those affected by PH. For details, call us at 301-565-3004 x767, or email giving@PHAssociation.org. Visit our website for more information at PHAssociation.org/Give.
Community Creativity Shines through Lantos Awards

Members of the PHA community have more than lived up to meeting the challenge of the Tom Lantos Innovation in Community Service Awards program by creating varied and, indeed, innovative approaches to awareness-raising and developing new and creative services for the PH community. We congratulate the winners, look forward to the impact these projects will make in the U.S. and abroad, and thank everyone who took the time to develop and submit a proposal for the 2011 awards program. PHA is grateful to Gilead Sciences for making this awards program possible.

Here’s a snapshot of the eight projects that are receiving funding this year.

» Everyone knows that living with PH can take an emotional, as well as a physical, toll on patients and family members. That’s why Spain’s Asociación de Hipertensión Pulmonar (ANHP), under the leadership of Juan Fuertes, is organizing a seminar on “Psychological Care for PH Patients.” The goal is to educate psychologists so they can provide professional care to PH patients, no matter where they live in Spain. It is also expected that the trained psychologists will inform their patients with PH about ANHP’s services.

» One of the great challenges that young adult female PH patients face is being told that they should not have children. Hannah Lahmeyer, a PH patient and adoptive mom, will be developing a “Guide to Building a Family while Having PH.” Hannah plans to work with a doctor, social worker and grief counselor to develop the content for this guide which will be widely distributed to the PH community and is particularly targeted to PHA’s Generation Hope, a group for patients in their late teens to early 30s.

» Donna Lain, who lost her daughter Kari Beth in 2003, wants to continue to give back to the PH community in Kari’s memory. That’s why she designed “Kari Bags,” which she will fill with age-appropriate toys, games and stress-relievers. “Kari Bags” will be distributed free-of-charge through pediatric PH specialists and centers as a way to brighten the day of kids who are living with PH. Donna hopes, too, that the bags will help educate adults and kids about the disease.

» Generation Hope member Colleen Brunetti will “Spread the Word” by developing public service announcements (PSAs) that highlight PHA’s email groups. These groups help connect patients and family members, reduce isolation and share tips for living better with PH. The PSAs will be promoted widely through PHA’s network of support groups as well as through members of PH Clinicians and Researchers and our PH Professional Network.

» In order to create a more cohesive PH community in Norway, PHA Norway, under the leadership of PH patient Hall Skåra, will host the organization’s “First Users’ Meeting.” Until now PHA Norway has functioned primarily through its website, but with this grant PHA Norway plans to bring together patients and caregivers from Nordic countries for the first time. A featured participant will be a patient from Germany who will help create links to other PH groups in Europe.

» Steve Van Wormer, dad to PH patient Lucas, will develop a series of “impactful, insightful and, most importantly, hopeful” digital public service announcements (PSAs) through a “PHA Viral PSA Campaign.” The PSAs will feature the PH journeys of patients, caregivers and medical professionals as well as information about PH. They will be posted on YouTube and Hulu and will be created so that they can also be featured on the radio, TV and in print.

» In Israel, Yosef Gotlieb, Joni Berg and Aryeh Cooperman will organize a “Symposium on Pulmonary Hypertension: Prospects for Progress” for PHA Israel. The group plans to hold an intensive one-day conference on PH for the medical, research and public health communities. Its goal is to inform professionals about the intricacies of diagnosis and treatment and the difficulties of living with PH. In addition, the organizers plan to hold a briefing about PH for health reporters and other media professionals.

» James “Dave” Rider will be raising awareness one step at a time as he walks across the state of Colorado in “Dave’s Walk of Hope, Awareness and a Cure for PH” — no simple feat for anyone, let alone for a PH patient. Dave’s plan calls for him to head out on Sept. 1, 2011, and complete his walk on Sept. 30, posting a daily video of the walk and the people he meets along the way.
When PHA hears about a specific insurance policy that is detrimental to the PH community, we advocate for change. Often this means working directly with the insurance company to improve its understanding of PH. Over the past few months, PHA responded to several unfavorable insurance policies — capturing victories for the entire PH community:

1. **The Problem:** In February 2011, Coventry Health Care in Ohio decided it would not cover Remodulin™ — or any prostacyclin — at doses greater than 40 ng/kg/min. This decision was made despite the fact that many PH patients are safely receiving treatment at doses of 100 ng/kg/min, or more, to achieve optimal benefit.

   **The Solution:** PHA teamed up with United Therapeutics to provide educational materials — including a letter from PHA’s Scientific Leadership Council (SLC) — to Coventry. Before another PH patient could be affected, Coventry adjusted its policy to cover higher doses of prostacyclin treatment based on the educational materials they received!

2. **The Problem:** BlueCross BlueShield (BCBS) of North Carolina eliminated coverage of combination therapy for oral PAH medications, claiming that such coverage is “investigational” and therefore subject to denial.

   **The Solution:** PHA’s SLC sent a letter to BCBS in support of combination therapy coverage. Then, Duke University’s Pulmonary Hypertension Center met directly with BCBS to advocate on behalf of their PH patients. PHA’s and Duke’s persistent advocacy and open dialogue with BCBS — along with letters from PH patients — convinced the company to reinstate combination therapy coverage for PH, in alignment with the SLC’s standard of care. Victory!

**Insurance Finds: Glossary of Terms**

“**My EOB** shows that I have a $7,000 **coinsurance** I have to pay **out-of-pocket** because my PH medication isn’t included on my **HMO’s formulary.**”

“**I need to obtain prior authorization** before **Medicaid** will approve a visit to my PH specialist because she is considered **out-of-network.**”

Navigating your insurance plan can be difficult enough without having to decipher insurance terminology. The PHA Insurance Glossary of Terms can help you make sense of insurance vocabulary. Visit [www.PHAssociation.org/Patients/Insurance/Glossary](http://www.PHAssociation.org/Patients/Insurance/Glossary) or call 301-565-3004 x773 to request a print copy.

If your insurance company is denying coverage for a PH-specific therapy, including combination therapy, let us know. While we can’t solve every problem, we may have resources that can help. Contact PHA at Insurance@PHAssociation.org or 301-565-3004 x773.
A Big Start!
The Tom Lantos PH Research and Education Act of 2011 was introduced just a few months ago, but PH advocates are already making headway:

- The inaugural National PH Call-In Day on April 26 generated more than 100 calls to Congress. Thank you to everyone who participated! Read more: p. 26.

Put a Face on PH: Schedule a Hometown Meeting with a Member of Congress this August!

This August, your Members of Congress will leave their Washington, D.C., offices and head to their home states to talk to constituents about the issues they care about. It’s a great opportunity to tell your senators and representative about the Tom Lantos Pulmonary Hypertension Research and Education Act of 2011 and how co-sponsoring the bill will bring us closer to new PH research and ultimately a cure.

Make the Most of District Visit Month this August:

- Schedule a visit with your Members of Congress in their local offices! Visit www.PHAssociation.org/Advocacy/Toolbox or contact Elisabeth Williams at 301-565-3004 x753 for contact information for your senators and representative as well as a sample script for requesting a meeting. Even if your Members of Congress have already co-sponsored the PH Research and Education Act of 2011, you can take this opportunity to say something they rarely hear — thank you. Invite family and friends to join you!
- Invite Members of Congress to your support group meeting! Last August Rep. Jason Altmire (D-PA) attended Merle Reeseman’s support group meeting. After spending more than an hour talking with and listening to PH patients, he announced his support for the Tom Lantos PH Research and Education Act. “When I get back to Washington, D.C., I will do everything I can to get my colleagues to co-sponsor this bill,” Representative Altmire announced. “It passed in the House before. We’ll get it to pass again.”

If meeting with your Members of Congress still seems intimidating, keep in mind they are human just like you. PH patient Diane Ramirez found that out the first time she met with one of her senators from North Carolina. “I was really nervous sitting there,” she recalls. “I was intimidated by his desk and all his pictures with the President and so on. Then, I looked down — he had no socks on! In my head I laughed. Then I relaxed and realized he was human. Yes, he has a position of authority and can help us, but he wasn’t wearing socks!”

Get started today by reviewing the resources on PHA’s website: www.PHAssociation.org/Advocacy/ConnectLocally.
Three Stories, One Outcome: Legislative Progress

Congressional Visit Yields PH Research Act Co-sponsor!

In February, PH patients Conchita Watson and Georgia Milosevic visited Rep. Chris Van Hollen’s (D-MD) district office in Rockville, Md., to encourage Rep. Van Hollen to co-sponsor the Tom Lantos Pulmonary Hypertension Research and Education Act of 2011.

Conchita first met with a member of Rep. Van Hollen’s staff last November after PHA’s Congressional Luncheon on Capitol Hill. In that conversation, she spoke about how the PH Research and Education Act would save the lives of PH patients. “The entire time, the staff member listened and was very attentive,” Conchita recounts.

After the Congressional Luncheon, Conchita immediately sent the staff member a letter thanking him for his time, reminding Rep. Van Hollen to co-sponsor the bill and offering herself as a resource for any PH-related questions. In reply, she received an invitation to visit Rep. Van Hollen’s district office to speak directly with him about the PH Research and Education Act.

At the meeting, Georgia and Conchita shared their PH journeys. “All of my doctors were too busy to help me,” Georgia explained to Rep. Van Hollen. “It wasn’t until I saw one of the young medical residents that I got my PH diagnosis.” Georgia emphasized that her journey toward a diagnosis was long, frustrating and not uncommon for many PH patients. In the couple of years it took for her doctors to properly diagnose her, Georgia went through bouts of depression and also wound up in the hospital two times because her doctors kept ignoring critical PH symptoms.

Conchita admits that she was a little nervous about the visit initially, but after she and Georgia shared their stories, Conchita knew they had made an impact. “I had a feeling … that he [Rep. Van Hollen] was going to do something about the bill. I could see that Georgia’s story really had an effect on him.”

Georgia says, “I can’t really emphasize enough how nice Van Hollen’s staff was to us. They took us into his office and really listened to us.” Shortly after their visit, Rep. Van Hollen officially co-sponsored the Tom Lantos Pulmonary Hypertension Research and Education Act of 2011. A visit from a constituent is the number one reason a senator or representative will co-sponsor our bill. Congratulations to both Conchita and Georgia! We’re one co-sponsor closer to a cure!

PHers Shout Out During National PH Call-In Day

I called my rep today. Took almost no time at all. By the time I was done, my fresh cup of coffee was still hot!
~ Colleen Brunetti, PH Patient

Members of Congress received more than 100 phone calls from PHers and their friends on April 26 — the inaugural National PH Call-In Day — urging them to support the Tom Lantos Pulmonary Hypertension Research and Education Act of 2011. That’s the most calls the PH community has ever made on a single day, and legislative staff can expect a lot more.

One activist not only called his own members of Congress but also emailed 300 friends to spread the call request beyond the PH community. Within 24 hours, two health legislative assistants on Capitol Hill had contacted Rep. Kevin Brady’s office to learn more about becoming an original co-sponsor of the bill, and many more congressional staff were doing their homework on pulmonary hypertension.

“It makes me really proud to see all the posts on here about people’s experiences calling their representatives today,” said Stuart Berwick about posts on Facebook in response to National Call-In Day. Chris Leber Morres added, “It’s a proud day for PH!”

Call-In Day might be over, but it’s not too late to contact your Members of Congress. Call today!
In April, PHA Board member Rev. Steve White traveled to Washington to help get the Tom Lantos Pulmonary Hypertension Research and Education Act of 2011 introduced with a good number of original sponsors. This is his story as recorded immediately after that visit.

I don’t know about you, but whenever I hear the First Amendment of the Constitution mentioned on the news, I usually think of freedom of religion, freedom of speech, a free press and our right to assemble. But it is when I exercise the last clause of the First Amendment that I am most aware of how unique our form of government is and of how proud I am to be an American. I am referring to our right to petition the government for redress of grievances.

I took full advantage of this right on Monday, April 4, when I joined our friends from PHA — Gavin Lindberg, Katie Kroner and Rino Aldrighetti — on Capitol Hill to visit the offices of my senators and congressman from Massachusetts and other members of the Massachusetts Congressional delegation to seek their support for the Tom Lantos Pulmonary Hypertension Research and Education Act of 2011 which will soon be introduced by Rep. Kevin Brady (R-TX) and Sen. Bob Casey (D-PA).

It was the perfect day to be in Washington. It was warm and sunny and the cherry blossoms and flowers were at their peak. And the reception we got from various congressional staffers was just as warm. Some of you may have met Sara Mabry, Sen. Casey’s legislative aide, at the PHA Congressional Luncheon. She is fully committed to helping us get our bill passed and is working closely with the senator and with Rep. Brady’s office to get the bill introduced soon.

My congressman, Rep. John Olver (D-MA), has been a longtime supporter of our efforts, and his staffer assured us that he will be an original co-sponsor this time as well. When we visited the office of Rep. Jim McGovern (D-MA), the congressman himself came out and said, “What’s up?” Gavin summed up our plea for him to be an original co-sponsor in less than 25 words and dropped the name of Tom Lantos, whom he knew had been a close friend of McGovern’s. At that, Rep. McGovern exclaimed, “The answer is ‘yes!’”

Other staffers we met listened attentively as we told them what PH is and why this bill is so important. I told them about my daughter Christen and how she had lived with PH for some time before she was finally diagnosed, in spite of many visits to the doctor for shortness of breath and other symptoms that I now know are classic signs of PH. We explained how the bill will help educate doctors and the general public about PH so that the disease can be diagnosed as early as possible and thus prolong life. At the end of every meeting, we asked the staffer to urge his or her boss to become a co-sponsor of our bill. And I reminded them that I’m from a huge French-Canadian family spread all over Massachusetts that really wants this bill passed. In fact, I think Gavin had the impression that I had more cousins at the end of the day than I had in the morning! It was an exhilarating day and a successful one.

Each of us has the right to do what I did on Capitol Hill. We all have the right to ask our government to help us solve problems that none of us can solve alone. Who else but the government would do anything to educate the public about a disease like PH? Who else but the government would focus research efforts on a disease that is unlikely to make big fortunes for drug companies?

So if you happen to be in Washington, or if you can make a special trip there like I did, drop in on your representatives. you’ll be surprised at what a warm reception you’ll get. Tell them your own PH story. Ask them to support our bill to fight PH. you’ll make a big difference, and you’ll feel the pride in America that I felt when I visited Capitol Hill on April 4.

Update: Thanks in part to the Rev. White’s visit, our bill was introduced with one Senate co-sponsor and five House co-sponsors.
Media Victories Educate Hundreds of Thousands about PH

Early in 2011, PH community members scored media successes with national audiences. In February, Dr. Steven Mathai, Assistant Professor of Medicine at Johns Hopkins University, and Debbie Castro, PHA Director of Volunteer Services and PH caregiver, appeared on The Kojo Nnamdi Show. In March, The Washington Post ran an article about PH patient Kimberlee Ford.

Dr. Mathai and Debbie educated more than 700,000 listeners about PH when they discussed symptoms, treatments and a typical day with the disease on the Washington, D.C., area-based NPR program. Their audience included one stunned caller who said, “Right now my chest is pounding because what you’ve said has opened up a flood gate inside of me. For the last 10 years, I’ve had problems where I could hardly walk up the stairs, or I couldn’t walk a block without having to stop and take a breath.”

In The Washington Post’s weekly feature, Medical Mysteries, Kimberlee Ford spoke about her struggle to do everyday activities prior to her PH diagnosis. Talking about the three flights of stairs she had to climb to get to her apartment, she said, “When I saw those steps, I saw mountains.” The feature focused on Kimberlee’s lengthy, frustrating journey to diagnosis. Kimberlee spent a year searching for answers while her symptoms grew worse. Eventually she ended up in a coma in a hospital intensive care unit. She woke up three days later.

After her doctors diagnosed her with severe primary pulmonary hypertension, Kimberlee recalled asking for a high blood pressure pill to help her with her condition. Since that moment, she’s sought to educate herself and her community about the disease.

Thanks to The Washington Post article and the NPR radio segment, hundreds of thousands of people who had never heard of PH will now be able to put a “face” to this disease. For tips and resources to help you connect with the media, contact Elisabeth Williams, PHA’s Grassroots Campaigns Associate. Email Elisabeth@PHAssociation.org, call 301-565-3004 x753 or visit PHA’s website at www.PHAssociation.org.

Paving the Path to a Cure with Research

PHA is proud of the many services, programs and opportunities for involvement we are able to bring to the PH community, but we know that our work will never be done until there is a cure for this dreadful disease.

That’s why we reach out to our community every summer and ask those who are able to be as generous as possible in support of PHA’s research program.

Our multifaceted research program supports both young and seasoned researchers. Recently we added a new program with the potential to lead to advances in the scientific understanding of PH, and we will soon fund research targeted specifically to pediatric PH patients.

Your research support not only does so much good, with funding from our research partners, your support almost doubles! Consider this: in 2010, PHA invested $522,500 in research and our partners contributed another $912,500!

Over time, these research investments really add up: Since the launch of PHA’s research program, we have expended $4,540,356 on research and leveraged $10,195,556 from our partners … an outstanding investment in every way.

Ready to make your own investment? Go to www.PHAssociation.org/Donate/SU11 to donate online or send a check in the enclosed envelope, noting it is for the “Summer Research Appeal.” Thank you!

Tackling PH Research from Many Angles

Here’s a brief rundown of the four research programs PHA currently funds in collaboration with our partners. And with funding from the Robyn Barst Pediatric Research Fund, we expect to add a fifth research program soon.

PHA/NHLBI Mentored Clinical Scientist Award (K08)/Mentored Patient-Oriented Research Career Development Award (K23). This program, a partnership with the National Heart, Lung, and Blood Institute, has awarded eight grants to junior investigators to date.

PHA/ATS/Pfizer Research Fellowship in Pulmonary Arterial Hypertension. This grant program, a partnership between PHA, the American Thoracic Society and Pfizer, has enabled us to support 10 faculty-level researchers through 2010.

PHA/AHA Postdoctoral Research Fellowship Award. In partnership with the American Heart Association, this award supports post doctoral Fellows, and PHA has made 24 awards to date.

PHA/Pfizer Proof of Concept Research Grants. This new partnership with Pfizer supports research projects in the early exploratory and developmental stages. We will make two awards in 2011.
Pathlight wins Best of Category!

Pathlight, the official newsletter of the PH community, received the 2011 Best of Category Award in the Printing and Graphics Association MidAtlantic Excellence in Print Awards. Pathlight won Best of Category in the newsletter division “in recognition of printing judged to be superior quality in the 2011 Excellence in Print Awards.”

The magnet is back!

PHA’s popular “PH Resources at Your Fingertips” magnet is back. Get yours through PHA’s online store (free materials) or by calling 301-565-3004 x0.

Request your magnet today!

Thank you, Interns!

PHA is grateful to our spring 2011 interns. They have made a real impact on the programs and services PHA is able to provide. To learn more about PHA’s internship program, visit www.PHAssociation.org/Internships.

Flora Wong, Patient Outreach & Services

During Flora’s internship at PHA, she worked closely with the redesign and improvement of the Envelope of Hope, a free information kit for newly diagnosed patients. She also assisted with identifying educational needs, researching topics of interest and developing new materials for PH communities. “Interning at PHA has been an extraordinary experience. I am lucky to have had the opportunity to work with professionals who truly believe in PHA’s mission,” she says. Flora received her Bachelor of Science in May 2011 from Virginia Commonwealth University, and she will continue her education at nursing school using her enhanced skills and experiences learned at PHA.

Chelsey Eberwein, Volunteer Services

This spring Chelsey helped PHA’s Volunteer Services team by calling support group leaders to offer support and information about PHA resources. She also assisted Debbie Castro, PHA’s Director of Volunteer Services, with the coordination of our weekly Volunteer Night. Chelsey’s grandfather, Frank Hetrick, was a PH patient who attended this weekly Volunteer Night with his wife Norma. Chelsey enjoyed her internship because it gave her the opportunity to connect with so many caring individuals. This fall Chelsey continues her education at the University of Maryland where she is a double major in Kinesiology and Women’s Studies.

Katie Anderson, Information Technology

Throughout Katie’s spring internship, she supported PHA staff in various areas of technology. She managed PHA’s email database, upgraded the operating system on staff members’ computers and scanned all computers to update an internal document of all software at PHA. “My most rewarding experience as an I.T. intern is helping the staff keep their technology running smoothly so they can carry out their tasks as needed,” Katie says. “I don’t work directly with the PH community, but I work in the background to make sure that the people who do work directly with the community are able to do the best job possible.” Katie will continue her work in information technology with an internship at Geico.
Spotlight on Support Groups: Santa Barbara

When you think of support groups, you probably don’t think of meetings in a zoo. But when the Santa Barbara Pulmonary Hypertension Support Group decided to host a very special (and fun!) meeting for its one-year anniversary last August, it brought their patients to the city zoo for socializing and a special dinner. Since PH patients talk openly about their condition, the only “elephants in the room” at this meeting were, quite literally, the elephants in the zoo! How about THAT for a support group celebration?

The Santa Barbara PH Support Group held its inaugural meeting in August 2009, and the group is still going strong. Meetings take place every three months with 30–50 patients and caregivers at each meeting. The group not only provides time for socializing, but offers medical presentations with experts in the field. Topics include insurance issues, dealing with hospitalizations, managing nutrition and diet, considerations for oxygen therapy and exercise, managing stress, emergency situations and much more.

The Santa Barbara Support Group started when Dr. Jeffrey S. Sager moved to Santa Barbara and went into private practice at Santa Barbara Pulmonary Consultants. Patients asked him to start a PH support group, and he did. Dr. Sager helps with meeting planning, and the two support group leaders include Dr. Sager’s nurse, Zoe Schultz, RN, MSN, and his wife, Dana. Even Dr. Sager’s children, Dylan (age 9) and Taryn (age 7), are familiar faces at the meetings.

Thank you to Dr. Sager, Dana, Zoe and the entire group! For more information about the Santa Barbara Pulmonary Hypertension Support Group, visit the group website [www.PHAssociation.org/SantaBarbaraGroup](http://www.PHAssociation.org/SantaBarbaraGroup) or contact the leaders by email at CA-SantaBarbara@PHASupportGroups.org.

By Debbie Castro
PHA Director of Volunteer Services

New PHA Telephone Support Group Launches in July

Have a hard time making it to a support group meeting? No group in your area? Or maybe you’re shy or just not sure a face-to-face support group meeting is for you? No problem. PHA is bringing the support group to YOU — straight to your home — via a telephone support group. Try it out!

Anyone in the U.S. can participate. The topic of the first meeting is “Getting to Know You.” Patients and caregivers can choose to share their story or simply listen in. Caregivers, also be on the look out for caregiver support group calls — coming soon!

Save the Date: Thursday, July 28, 8 p.m. ET

Contact Debbie Castro for more information and to receive the dial-in number and access code for the support group call: Debbie@PHAssociation.org or 301-565-3004 x755

Don’t forget! For telephone support during ANY time of the year, contact our Patient-to-Patient Support Line: 800-748-7274.
The PHA Support Group “Scoop”

With more than 235 support groups nationwide, meeting monthly to quarterly, we’ve got some great stories from support group meetings to share. This new Pathlight feature will give you a snapshot on trends, news, views, and the latest and greatest from support group meetings occurring around the U.S.! Get a firsthand look into all the great ways PH patients are taking advantage of being a part of a support group.

• **Chair yoga** has been all the rage with support groups in the South! We’ve seen chair yoga meetings in South Carolina and now in Pensacola, Fla. Support group leader Donna Head told us she “had a blast” and is “now hooked on chair yoga!”

• Did you hear? Fort Worth and Dallas, Texas, groups had a **joint meeting** near the Cowboys stadium. In spite of the temptation to go straight to the game, the groups had more than two dozen patients and caregivers in attendance and even picked up some new members!

• Dozens of support groups across the country got a healthy dose of advocacy by participating in **PHA’s National Call-In Day**. For one, Del Val, Penn., Support Group members called their Congressionals representatives throughout the day and felt accomplished after speaking with the offices of so many members of Congress. The Newport Beach, Calif., Support Group also had a great experience with advocacy that day. The group leader, Chris Morres, says she “called Senator Feinstein’s office and was shocked to hear they had already received several calls!”

• Safety first! The Piedmont Area Support Group in North Carolina invited a sheriff speak at a recent meeting to discuss how to handle different **safety situations** in the surrounding areas. According Diane Ramirez, one of the group leaders, the sheriff was “a very funny speaker” and the group had a fantastic time: “It was nice to be in the meeting talking about other life issues — not just PH!”

• Rainy weather and bad drivers in the streets of Washington, D.C., didn’t wash out the D.C. Capital Breathers support group meeting. This group had a great turnout and members were very interested in hearing the **speaker talk about his experience as a pastor, a cancer survivor and a caregiver to Kim Ford, PH patient and support group leader.**

• The Morristown, N.J., Support Group had phenomenal turnout for its April meeting. About 30 people came together for a talk by a **Caring Voice Coalition expert**. Did you know this organization helps PH patients with services like insurance counseling, legal assistance for disability applications, peer mentoring and need-based financial assistance? For more information, visit [www.CaringVoice.org](http://www.CaringVoice.org)

• The Fresno, Calif., Support Group had a great turnout at its March meeting. With a **speaker from Stanford Medical**, the group had 34 people show up, including three newly diagnosed patients. What a great example of what PHA support groups are all about — bringing support to both new and veteran PH patients!

• Chew on this: The Buffalo, N.Y., Support Group is taking **nutrition** to a new level. The group leader, Jaclyn Burdick, is collecting low-fat, diabetic-friendly recipes to share among group members.

• Two leaders from New York and Ohio are coordinating the **creation of quilts** to be showcased at PHA’s 2012 International PH Conference. One quilt will pay tribute to the memory of those we have lost to this disease, and the other will focus on support groups. Talk about a great way to “weave” together the common “threads” among support groups!

• The Rocky Mountain Support Group of Denver got down to business! They welcomed **PHA Board Member John Hess as the speaker** for its March meeting. John, whose son is a 12-year-old PH patient, told the group about the latest in PHA news, research updates, and future goals for 2011.

By Chelsey Eberwein
Former PHA Volunteer Services Intern
This June, PHA traveled the country with *PHA on the Road: PH Patients and Families Education Forums*, making stops in Seattle, Pittsburgh, St. Louis and wrapping up on June 18 in Minneapolis. What does it mean for a local support group when *PHA On the Road* comes to town? We checked in with the leader of a local Minneapolis support group to see what effect *PHA On the Road* had on her group.

The Twin Cities Support Group is no stranger to events such as this; Minneapolis was, in fact, the location of PHA’s 2006 International PH Conference and Scientific Sessions. Six years later, and with many new faces, the group couldn’t be more thrilled to have its city selected for *PHA on the Road*. Twin Cities Support Group leader Stephanie Layer loves what these events have done to strengthen the group: “[They are] well-orchestrated, full of information, very fun and educational. I met a lot of people, and a lot of information was shared.”

At *PHA On the Road*, attendees got a chance to listen to area doctors speak about different aspects of living with and treating PH, and they also got a chance to ask doctors questions about the disease. This interaction helped build relationships between those living with PH and the medical professionals who treat them. Stephanie emphasized this as one of the top reasons for attending a forum: “[It is] important for the doctors to know the patients in a setting outside of the office. After you’re diagnosed, you have a lot of time to think, time to think of more questions, and this is a more relaxed atmosphere to talk in than the office.”

Leading up to *PHA on the Road*, support group meetings helped prepare members for the experience so they could get the most out of it. Stephanie encouraged patients and their families to come to the events ready to sit in on as many talks as possible, and she also encouraged them to ask questions: “This is the time to hear about new treatments and connect with other patients. It’s like a mini-conference.”

Support group presence at educational programs like *PHA On the Road* can also increase involvement and participation in local support groups. For those who had never met another patient before attending *PHA on the Road*, the forum helped show them that there is a lively community and other people dealing with the disease. The forum provided an ideal time for support group leaders and their members to reach out to potential new members who could benefit from the groups. The Twin Cities Support Group members hope to see an increase in group participation later this summer when they host their annual celebratory picnic for PH patients and family members. In 2010, 131 people attended, and they are certain that advertising at *PHA on the Road* will bring even more people this year.

By Sophie Klein
PHA Volunteer Services Associate

**Traveling for *PHA on the Road***

While *PHA on the Road* was a chance for Minneapolis PH patients to make connections with other locals dealing with the disease, some attendees at the forum came quite a distance to be there. For Janice Howd, the leader of the Sioux Falls, S.D., Support Group, *PHA on the Road* was an opportunity worth traveling to experience. Janice and members of her group crossed state lines and traveled 280 miles from Sioux Falls because “there aren’t many with PH in South Dakota, and it’s important for me to go and bring back as much knowledge as I can for our members,” she says. Janice felt the trip was worthwhile because she had the opportunity to learn, meet other leaders and enrich her group through what she learned.

*PHA on the Road* reached four cities this June, but its impact reached far beyond those four state borders. As a result, patients from both nearby and far away left the forums better informed and, possibly, with some new friends.
Support Group Leaders: Find Resources, Support in One Place Online

Leading a support group can be fairly simple and easy, but sometimes it can feel a bit overwhelming. PHA has created an online Support Group Leader Resource Center where you can find all of our leader resources. We’ve also added easy forms for submitting information to PHA.

In the Resource Center you can:

- Submit a Support Group Central Fund application (for financial support for food at your meetings)
- Update your public contact information
- Submit meeting information for a postcard mailing to PHers in your area
- Access free materials, sample fliers and images to use in your materials
- Find tips for advertising your group’s events
- Watch recordings from our Second Tuesday monthly leader trainings
- Review the Support Group Leader Manual
- Learn simple tips for keeping your group’s site up-to-date with minimal effort or technical know-how
- Watch how-to tutorial videos on how to update your group’s website

Support group leaders, visit the Resource Center today at www.PHAssociation.org/SGLResourceCenter (you will be prompted to sign in).

Not a leader, but interested in starting a group? Contact us! SupportGroups@PHAssociation.org or 301-565-3004 x755.

Orlando, Fla., Support Group Connects with PHA’s Board of Trustees

More than 60 Orlando-area patients and caregivers took advantage of a special PHA support group meeting in March. PHA’s Board of Trustees meets periodically in strategic locations across the country. Whenever they meet, PHA tries to host a special support group meeting so Board members and staff can connect with the local community and vice versa.

At this special meeting, Board member and former Board chair, Carl Hicks, discussed his adventures lobbying decision-makers for PH research, education and awareness. Patients shared their journeys with PH and their victories in the PH community, including fundraising successes and lobbying efforts.

To round out the meeting, Debbie Castro, PHA Director of Volunteer Services; and Doreen Lucadamo, PHA’s Director of Meetings and Conference Planning, spoke about PHA’s International PH Conference and Scientific Sessions which will take place in Orlando in 2012, and opportunities to get involved in volunteering in the months leading up to the event.

Orlando Support Group leaders Melissa (right) and Dan Quevedo met PHA founder and Board Emeritus, Dorothy Olson (center).

See you in Orlando for PHA’s 2012 International Conference!
On April 9, the Inaugural Walk 2 Cure PH: Ellie Godina Memorial Walk was held in Euclid, Ohio. The event honored 2 ½ -year-old Ellie, who lost her battle with pulmonary hypertension in 2010.

For months, doctors could not determine the cause of Ellie’s symptoms. Ellie was eventually diagnosed with acute PH. Tragically, she passed away only two days after the diagnosis. Amid their grief, Ellie’s parents, Missy and Joe Godina, vowed to raise awareness about the often-misdiagnosed disease. Missy says, “We wanted to raise awareness and funds for a cure so that other families won’t have to go through the same thing.”

And raise awareness and funds they did. Missy, Joe and their Walk 2 Cure PH committee created a special event that brought an entire community together. The event drew nearly 400 participants for a three-mile walk at Euclid High School and offered something for everyone — everything from a kids’ corner with giveaways, face painting and a balloon artist to educational tables representing industry and area hospitals. The event even kicked off with entertainment by the Euclid High School marching band. The Walk 2 Cure PH raised more than $31,000 for PHA’s research program and programs for patients and their families. PHA spoke with Missy after the event to learn about the various pieces that went into creating this successful fundraiser.

Goals for Walk 2 Cure PH

In addition to their desire to raise awareness and funds for PH research and patient programs, Missy and Joe wanted to create a walk that would “keep Ellie’s memory alive, and keep her legacy moving forward,” says Missy. Since the date of the event, Missy continues to receive feedback from the Euclid community describing the ways Ellie has touched others. “People feel they know her through the walk,” Missy says. “I now see people driving around with the [PH awareness] ribbon car magnet. It’s amazing how many know about PH now, when just one and a half years ago, I didn’t even know what it was.”

Participants & Publicity

Largely because of word-of-mouth marketing, Walk 2 Cure PH gained a huge amount of momentum early in 2011. On the day of the walk, as threats of rain dissipated, 90 walkers registered on-site, bringing total attendance to nearly 400. “It was a really mixed crowd — old, young, even newborns,” says Missy. Her background as a teacher garnered substantial involvement from the local public schools, and Missy and her committee planned several “mini” fundraisers throughout the preceding fall and winter to drum up excitement for the early spring walk, including a “change war” at Missy’s school, which was covered by a local TV affiliate.

Volunteers

It takes a village … to put on a special event! In addition to an event planning committee of eight, Missy had more than 60 volunteers who helped with a multitude of planning tasks and who ensured everything went smoothly on the day of the walk. Friends and neighbors greeted walkers on arrival and sold raffle tickets. Local teens ran the face painting and kids’ corner. For all their hard work, the Godinas made a point to publicly acknowledge each volunteer during the walk.

Special Guests

The Godinas were successful in getting various civic and PH community leaders to support the Walk 2 Cure PH. The mayor of Euclid and the superintendent of Euclid City Schools both attended, and as a result, each pledged endorsement of next year’s walk. PH patient Merle Reeseman, an active leader in the Cleveland-area PH community, delivered the keynote speech. Shari Caffrey, organizer of Race 2 Cure PH in Anaheim, Calif., lent advice and friendship throughout the planning process and traveled from California to attend.

Why It Matters

The Godinas chose to host Walk 2 Cure PH because they knew it was one way to create something positive out of grief. “The whole theme rotated around Ellie and the memories we have of her,” says Missy. She recalls when a student volunteer sang “Over the Rainbow” before the walk began. For a variety of reasons, the Godinas see rainbows as symbolic of their daughter. “A rainbow is just
Energy Abounds in PHA’s Spring Special Events

Spring was an exciting time for PHA Special Events with many fun walks, golf tournaments and themed events. From first-time fundraisers to fifth-year mainstays, take a look at snapshots from a few of these incredible events!

Learn more about PHA Special Events by visiting www.PHAssociation.org/SpecialEvents or contacting Jessica McKearin, PHA’s Associate Director of Special Events, at Events@PHAssociation.org or 301-565-3004 x765.

Event: Spur a Cure for PH  
Location: Phoenix, Ariz.  
History: Fifth Annual  
Attendance: Approximately 150 participants  
Pictured Above: The welcome committee and event co-chair Amy Moseley (right) are ready to go!  
Fun Fact: The western-themed event featured a musical performance by Nashville recording artist Sheylyn Jaymes!

Event: Scramble for a Cure Golf Tournament  
Location: Las Vegas, Nev.  
History: Third Annual  
Attendance: Approximately 100 participants  
Pictured Above: Eager golfers prepare to hit the course!  
Fun Fact: This year’s tournament featured a helicopter ball drop!

Event: Cure PH Golf Tournament and Luncheon  
Location: Clemmons, N.C.  
History: Fifth Tournament  
Attendance: Approximately 75 participants  
Pictured Above: PH patient Bailey Brewer and her grandmother enjoy the luncheon.  
Fun Fact: The tournament was held at the renowned Salem Glen Golf & Country Club, a Jack Nicklaus-designed course!

Event: Dunwoody High 5K  
Location: Dunwoody, Ga.  
History: Inaugural  
Attendance: More than 160 walkers/runners and many more volunteers  
Fun Fact: The high school students planning the event chose PHA as one of three beneficiaries, along with Autism Speaks and the school’s graduating class of 2013. Nearly $1,700 was raised for PHA in memory of Eve Greenstein.
August 2011
Now is the perfect time to start planning your November PH Awareness Month fundraising event! Email Events@PHAssociation.org or call 301-565-3004 x765.

Tuesday, Aug. 30, 2011
PHA Fundraiser at Iron Pigs Baseball Stadium
WHERE: Allentown, Penn.
DETAILS: Joan Stevenson at jsteve@ptd.net or 610-841-1942

September 2011
The year’s third issue of Event-ful Times is distributed at the end of the month. Make sure that you’re on the list to receive this PHA Special Events publication! Sign up at www.PHAssociation.org/SpecialEvents/OrganizeAnEvent. Questions: Email Eventful@PHAssociation.org

Sunday, Sept. 18, 2011
Colorado Pulmonary Hypertension Run for PHun 2011
WHERE: Anschutz Medical Campus, Aurora, Colo.
DETAILS: Deb McCollister at Deb.McCollister@ucdenver.edu or Beth Coleman at Coleman.Beth@tchden.org

Friday, Sept. 23, 2011
New England PH Forum
WHERE: HomeWood Suites, Scarborough, Maine
DETAILS: Jeannette Morrill at 207-695-3042 or jeannettem@myfairpoint.net

Saturday, Sept. 24, 2011
Swinging for a Cure Golf Tournament
WHERE: Webhannet Golf Club, Kennebunk Beach, Maine
DETAILS: Jeannette Morrill at 207-695-3042 or jeannettem@myfairpoint.net

Saturday, Oct. 8, 2011
8th Annual Georgia Fun Walk
WHERE: Marietta, Ga.
DETAILS: Sally Maddox at 706-331-0938 or skshmaddox@yahoo.com

Friday, Oct. 14, 2011
6th Biennial Rochester PHA Gala
WHERE: DoubleTree Hotel, Rochester, Minn.
DETAILS: Bonnie McGoon at 507-269-3267 or bonmcgoon@gmail.com

Welcome Leslie Mahaney, Special Events Associate!
As PHA’s Special Events Associate, Leslie is responsible for working with PHA’s veteran volunteer event planners to ensure they have all the tools needed to plan and implement successful fundraisers for PHA’s research program and patient services. Leslie also maintains the resources PHA’s Special Events program provides to its volunteers, including the production of Event-ful Times, the Special Events e-newsletter. Leslie has a clinical background in Child Life and has worked within a hospital setting to enhance the quality of life of patients and families. Leslie can be reached by phone at 301-565-3004 x742 or email at Leslie@PHAssociation.org.

For more Special Events coverage, visit www.PHAssociation.org/SpecialEvents

WALK TO CURE PH STORY CONTINUED FROM PAGE 34

Welcome Leslie Mahaney, Special Events Associate!
As PHA’s Special Events Associate, Leslie is responsible for working with PHA’s veteran volunteer event planners to ensure they have all the tools needed to plan and implement successful fundraisers for PHA’s research program and patient services. Leslie also maintains the resources PHA’s Special Events program provides to its volunteers, including the production of Event-ful Times, the Special Events e-newsletter. Leslie has a clinical background in Child Life and has worked within a hospital setting to enhance the quality of life of patients and families. Leslie can be reached by phone at 301-565-3004 x742 or email at Leslie@PHAssociation.org.

Looking Ahead
Because of the overwhelmingly positive feedback, planning is already underway for the 2nd Annual Walk 2 Cure PH, which is set to take place in late April 2012. “We raised a lot more funds than I ever thought possible,” Missy says. “It’s truly amazing how generous people are. The community involvement was fantastic.”

By Jessica McKeain, PHA Associate Director of Special Events

a piece of her,” says Missy. “Every time I’m having a bad day, a rainbow appears.”

They also know that choosing and hosting a successful fundraiser will help PHA actively work toward a PH cure by sponsoring cutting-edge medical research and continuing to provide a community of hope for patients and families affected by PH.

For more Special Events coverage, visit www.PHAssociation.org/SpecialEvents

By Jessica McKeain, PHA Associate Director of Special Events

Welcome Leslie Mahaney, Special Events Associate!
As PHA’s Special Events Associate, Leslie is responsible for working with PHA’s veteran volunteer event planners to ensure they have all the tools needed to plan and implement successful fundraisers for PHA’s research program and patient services. Leslie also maintains the resources PHA’s Special Events program provides to its volunteers, including the production of Event-ful Times, the Special Events e-newsletter. Leslie has a clinical background in Child Life and has worked within a hospital setting to enhance the quality of life of patients and families. Leslie can be reached by phone at 301-565-3004 x742 or email at Leslie@PHAssociation.org.

Looking Ahead
Because of the overwhelmingly positive feedback, planning is already underway for the 2nd Annual Walk 2 Cure PH, which is set to take place in late April 2012. “We raised a lot more funds than I ever thought possible,” Missy says. “It’s truly amazing how generous people are. The community involvement was fantastic.”

By Jessica McKeain, PHA Associate Director of Special Events

Welcome Leslie Mahaney, Special Events Associate!
As PHA’s Special Events Associate, Leslie is responsible for working with PHA’s veteran volunteer event planners to ensure they have all the tools needed to plan and implement successful fundraisers for PHA’s research program and patient services. Leslie also maintains the resources PHA’s Special Events program provides to its volunteers, including the production of Event-ful Times, the Special Events e-newsletter. Leslie has a clinical background in Child Life and has worked within a hospital setting to enhance the quality of life of patients and families. Leslie can be reached by phone at 301-565-3004 x742 or email at Leslie@PHAssociation.org.

Looking Ahead
Because of the overwhelmingly positive feedback, planning is already underway for the 2nd Annual Walk 2 Cure PH, which is set to take place in late April 2012. “We raised a lot more funds than I ever thought possible,” Missy says. “It’s truly amazing how generous people are. The community involvement was fantastic.”

By Jessica McKeain, PHA Associate Director of Special Events

Welcome Leslie Mahaney, Special Events Associate!
As PHA’s Special Events Associate, Leslie is responsible for working with PHA’s veteran volunteer event planners to ensure they have all the tools needed to plan and implement successful fundraisers for PHA’s research program and patient services. Leslie also maintains the resources PHA’s Special Events program provides to its volunteers, including the production of Event-ful Times, the Special Events e-newsletter. Leslie has a clinical background in Child Life and has worked within a hospital setting to enhance the quality of life of patients and families. Leslie can be reached by phone at 301-565-3004 x742 or email at Leslie@PHAssociation.org.

Looking Ahead
Because of the overwhelmingly positive feedback, planning is already underway for the 2nd Annual Walk 2 Cure PH, which is set to take place in late April 2012. “We raised a lot more funds than I ever thought possible,” Missy says. “It’s truly amazing how generous people are. The community involvement was fantastic.”

By Jessica McKeain, PHA Associate Director of Special Events

Welcome Leslie Mahaney, Special Events Associate!
As PHA’s Special Events Associate, Leslie is responsible for working with PHA’s veteran volunteer event planners to ensure they have all the tools needed to plan and implement successful fundraisers for PHA’s research program and patient services. Leslie also maintains the resources PHA’s Special Events program provides to its volunteers, including the production of Event-ful Times, the Special Events e-newsletter. Leslie has a clinical background in Child Life and has worked within a hospital setting to enhance the quality of life of patients and families. Leslie can be reached by phone at 301-565-3004 x742 or email at Leslie@PHAssociation.org.

Looking Ahead
Because of the overwhelmingly positive feedback, planning is already underway for the 2nd Annual Walk 2 Cure PH, which is set to take place in late April 2012. “We raised a lot more funds than I ever thought possible,” Missy says. “It’s truly amazing how generous people are. The community involvement was fantastic.”

By Jessica McKeain, PHA Associate Director of Special Events
In June, **PHA on the Road: PH Patients and Families Education Forums** made stops in four new cities: Seattle, Pittsburgh, St. Louis and Minneapolis. These regional forums brought together patients, caregivers, family members and medical professionals alike to provide exciting educational sessions, which covered everything from the basics of PH to lifestyle issues.

PHA thanks all those who attended and participated in the 2011 **PHA on the Road** forums. The success of this program, since its inaugural year of 2009, has been in large part due to the desire of the PH community to gain more education and understanding of this disease. Attendees traveled from far and wide to attend these forums, some driving almost 500 miles to attend this full-day program!

PHA also thanks Dr. Paul Fairman, National Committee Chair of the 2011 **PHA on the Road** program, the members of the **PHA on the Road** regional committees and the many speakers who participated in these forums. Thanks to your dedication and hard work, we brought information on a variety of PH topics into the hands of patients and their family members.

Look for a full recap of the 2011 **PHA on the Road** forums in the Fall issue of *Pathlight*. PHA plans to go back “on the road” in 2012 — so stay tuned. We may be visiting your city next!

For more information about the **PHA on the Road** program, including photos from this year’s forums, visit [www.PHAssociation.org/OnTheRoad](http://www.PHAssociation.org/OnTheRoad).

---

**Summer Special: PH Awareness Combo Pack!**

Help raise awareness while saving money!

Get a PHA Hat, Water Bottle and Two Wristbands for $15!

*Purchased separately, items total $21.*

Only PHA Members are eligible for this special, limited-time offer. Order now through Oct. 1 at the PHA Online Store, [www.PHAssociation.org/Store](http://www.PHAssociation.org/Store) or give us a call.

Not a member? Visit [www.PHAssociation.org/Join](http://www.PHAssociation.org/Join) to become a member of PHA today!

Questions? Call the PHA Office at 301-565-3004.
Building Medical Education in PH
A Partnership Initiative to Advance Medical Understanding of Pulmonary Hypertension

Pulmonary Hypertension:
An update on evaluation and treatment
Mayo Clinic, Jacksonville
Aug. 27, 2011
Jacksonville, Fla.
Email: cme-jax@mayo.edu
Call: 1-800-462-9633
Website:
www.mayo.edu/cme/pulmonary-medicine-2011j953

Pulmonary Vascular Symposium
Eric P. Newman Education Center
Washington University Medical Center
Oct. 15, 2011
St. Louis, Mo.
Email: cme@wustl.edu
Call: 1-800-325-9862
Website:
http://cme.wustl.edu/pulmonary

To view a full list of education opportunities for medical professionals, visit www.PHAOnlineUniv.org/Calendar

---

A Cause for Celebration!
PHA said to “outperform most other charities in America”

In recognizing PHA for the eighth consecutive year with a 4-Star (the highest) rating, Charity Navigator President and CEO Ken Berger noted that this indicates that PHA “outperforms most other charities in America” — and is an achievement reached by only 2 percent of charities in the U.S.

Charity Navigator, America’s premier charity evaluator, went on to say that this designation “differentiates PHA from its peers” and signifies that we execute our mission “in a fiscally responsible way.”

For more information, go to www.PHAssociation.org/CharityNavigatorRating

---

SAVE THE DATE!
PHA’s 10th International Pulmonary Hypertension Conference and Scientific Sessions
June 22-24, 2012
Renaissance Orlando at SeaWorld®
Orlando, Fla.
Visit www.PHAssociation.org/Conference and learn about the latest breaking news about Conference by signing up for our early alert email list!
INTERVIEW WITH PH PATIENT
KENDRA SULLIVAN

Interview conducted by Mira Kruger
PHA Pathlight Volunteer

Where do you live?
I live in Port Angeles, Wash.

How old are you?
I am 11 years old.

When were you first diagnosed?
I was diagnosed in the summer of 2006, right before I started second grade.

When did you first start having symptoms of pulmonary hypertension?
I had my tonsils taken out, and my oxygen levels kept dropping after that surgery.

What were your symptoms?
I don’t really remember having symptoms, but my mom said I used to just stop sometimes while I was playing.

What activities do you like to do?
I love to read and color. I also like playing on the computer and riding my adult-sized tricycle.

Have you ever felt unable to do something because of PH?
I can’t play sports, but that’s okay because I don’t really like sports anyhow. I can still play on the swing at the park, though, because I have a backpack for my oxygen.

How has your life changed since you’ve been diagnosed with PH?
I am homeschooled now because going to school full time was too tiring. I like being homeschooled because I can work on what I want when I want.

What is a message you’d like to pass on to other kids with PH?
Don’t worry if you have to get a central line. It might bother you a little bit at first, but it doesn’t hurt. Sometimes I even forget it’s there.
Can I ask you something? I don’t want to make you mad or hurt your feelings, but I’m just curious,” a girl asked me one day after school.

“Here it comes. She is going to ask about my health,” I thought to myself. I can always tell when people are going to ask a question about my health. Almost everyone starts off with “I don’t want to be rude, but can I ask you something?” The questions are usually about the big, bumpy, bright pink scar I have going down my chest, or why my voice sounds so raspy. Both are from multiple open heart surgeries to replace my pulmonary valve.

While this girl was sensitive towards me and my feelings before asking about my health, I have had incidents where other people are not as sensitive. I have had people make comments such as: “So you don’t mind drawing attention to your scar?” I even had someone look at a picture of me, put her hand over my scar and say, “You’d look way better if you didn’t have that.”

There are times when I know that people are making comments just to be mean and hurtful. I still don’t understand why people say the things they say. Maybe they aren’t thinking before they speak. I’m not sure, but I do know that I want people to realize that words, even if you don’t mean them in a rude or nasty way, can and do hurt people. And they do make people feel uncomfortable and sometimes even ashamed of not only themselves but their own body. Sometimes I don’t like how my body looks. There are times when I wear a bathing suit in public and I can’t help but feel insecure when I look at all the girls who have chests without a bright pink scar going down the middle. But I have grown to accept my scar and how my body looks. It has taken me a while to get to where I am today. Do I like my scar? Heck no. But I am glad I have it, because it means I am alive.

Having PH, I know that there are people out there who get comments about the IV tube coming out of their shirt. I know the pain, sadness and self-consciousness that come from these insensitive questions/comments. However, when people ask questions or say something that seems rude or insensitive, I remind myself that they most likely did not mean to be rude. I tell myself that if I answer their questions with a smile, then I can help bring awareness to PH.

I urge all of you, the next time someone makes a rude or insensitive comment about how you wear oxygen, have a tube coming out of your shirt or why your lips look blue, kindly turn to them and explain what is going on with your body. We can make a difference in the way the world sees those who are different by sharing our stories of survival.

By Becca Atherton
PH Patient

Meet Becca and other teens who have PH at www.PHATeens.ning.com. PHA Teens is a secure social networking site for teens age 13-18 who have PH.

Becca won a 2011 Person of Character Award at her high school in Scottsdale, Ariz. Recipients of this award “believe in the inherent dignity of all people and treat everyone with respect, even those whose ideas and ideologies evoke strong disagreement. They have a strong sense of right and wrong and have the courage and willpower to do the right thing even when it is unpleasant, costly or goes against what others are doing.” Becca’s award includes a scholarship for college. Congratulations, Becca!
Growing Independent through Technology

My daughter Camille was diagnosed with pulmonary hypertension 17 years ago. When she began attending college, we wanted to improve the connection between our daughter and her PH specialist. This was particularly important to us given that under HIPAA privacy laws, the doctor needs permission to talk to us as parents about any medical information.

Although Camille was comfortable communicating face-to-face with her PH team, transitioning to phone communication was a challenge. Early on, we began encouraging her to call her specialist if she had questions or concerns, but Camille always found excuses not to call.

Then we thought: how do we make it easier for her to communicate with her physician? She enjoys texting or emailing. Camille’s specialist agreed to share his email address, and emailing seemed less imposing and more comfortable to her than talking on the phone.

Once she became comfortable emailing her specialist, we focused on providing Camille with a data plan so that she could write and check emails on her phone. Her college connected her with a federal program under the Federal Rehabilitation Act of 1973 that helps students with disabilities afford items that support their college career. Camille’s specialist wrote a letter requesting that the program cover the cost of her cell phone data plan.

Having email access on her cell phone allows Camille to communicate with her PH team without pulling out her laptop. She can schedule appointments discreetly without calling the specialist’s office in front of her roommates. It allows her to be independent and travel. Most importantly, it has allowed her to develop an independent relationship with her specialist.

If a situation comes up while she is away from home, she feels comfortable calling her specialist. In emergencies, she knows not to rely on email. Email allows her to ask questions before a situation arises in which she does not know what to do. Having this connection has been a relief for us as parents.

When Camille was traveling south and wanted to know whether the ocean or the pool would be safer for swimming, her specialist strongly advised against swimming in the ocean, describing it as a “soup of bacteria.” His words convinced her not to try it, whereas she might have ignored the same advice if it had come from me.

Letting Camille become independent and travel by herself has been difficult for me as a parent. The first time she was planning to fly by herself out of state, I was so anxious that I almost canceled the trip. Her specialist reassured me plans were in place in case anything happened, and the trip was a success. Being able to share my concerns and knowing we weren’t alone in making the decisions was comforting. As a parent, watching Camille become more independent through life’s experiences has been a dream come true.

By Nancy Frede, Mother of PH Patient Camille Frede

Connect with Other Parents of Kids with PH through PHA’s Parents Telephone Support Group

“For months after [my daughter’s] diagnosis, I couldn’t find anything. [I appreciate] getting to talk with other parents, and you have good speakers, good topics. Every time I hang up, I have learned something or I just feel better.” ~ Jane

The Parents Telephone Support Group calls offer a toll-free telephone support group for caregivers of children with PH. Calls are held on the third Thursday of every month at 8:30 p.m. ET/5:30 p.m. PT.

Upcoming calls:

Check the upcoming schedule, including topics and speakers, anytime at www.PHAssociation.org/Parents/Support
**Passages**

is PHA’s way of honoring those who have lost their battle with PH, as it has been since the very first Pathlight was published in May 1990. As we learn of patients’ passing, we inform the PH community. PHA extends sympathy to the families and friends of those who are gone but not forgotten; each Pathlight is dedicated to their memory.

**Donations Listed Were Received Between March 1, 2011, and May 31, 2011.**

PHA is deeply grateful to the PH community for its extraordinary support.

**Take a Look! Sustainers Circle Members Recognized**

PHA now recognizes members of our Sustainers Circle in the donations lists. Look for a ⊗ symbol to see who has made a sustained commitment to donate to PHA on a monthly basis. If you are not a member of our Sustainers Circle but are interested in joining, visit [www.PHAssociation.org/Donate/SustainersCircle](http://www.PHAssociation.org/Donate/SustainersCircle) or call Jennifer at 301-565-3004 x756. You may also use the remittance envelope enclosed in this issue of *Pathlight*.

**In Memory Of**

The accuracy of this list is very important to us. Please contact the PHA office at 301-565-3004 x756 or Jennifer@PHAssociation.org to have a recently deceased loved one’s name listed in Passages or to report errors or omissions.

For those for whom it would be helpful, PHA has developed a resource, *Mourning a Loved One: A Guide to Grieving*, which is available at [www.PHAssociation.org/Caregivers/Bereavement](http://www.PHAssociation.org/Caregivers/Bereavement). For more information, or to request a print version of this guide, please contact Bereavement@PHAssociation.org or 301-565-3004 x800. We welcome all loved ones to remain a part of our community for as long as it is beneficial.

**Donations Listed Were Received Between March 1, 2011, and May 31, 2011.**

PHA is deeply grateful to the PH community for its extraordinary support.

**Delta Zeta Epsilon Sigma Chapter of Wayne State University**

**Mariann and Dennis D’Hondt**

**Mr. Ranjan D’Mello**

Ms. Cathleen Dueweke

Ms. Jacqueline F. Floyd

Ms. Viola Hadgikosti

Mrs. Melora Hamann

Kostantinos and Deborah Kapordelis

Angela, Chuck, Elizabeth Anne and Matthew Kennedy

The Larson Santrock Family

Mrs. Lin Leong

Thomas and Cheryl Liebold

Michael and Janet Moore

Mrs. Terri Morath

Mrs. Lydia B. Rustmann

Mrs. Carol Sanders

Mrs. Therese Schrage

Miss Patricia Wiley

**Joan Winters**

**Mr. Robert A. Comilla**

**The Cullen Family**

**Mrs. Lin Leong**

Thomas and Cheryl Liebold

Michael and Janet Moore

Mrs. Terri Morath

Ms. Diana M. Richards

Mrs. Lydia B. Rustmann

Mrs. Carol Sanders

Mrs. Therese Schrage

Mrs. Chen Trefney

Miss Patricia Wiley

**Joan Winters**

**DELORES AARON**

Mr. Paul R. Belting

Ms. Janice F. Howd

Ms. Rose N. Johnson

**MARITZA M. ALICIA**

Mr. Christopher Erdman

**MONICA G. ALLEN**

John and Patricia Allen

Mr. Peter Marino ⊗

Mr. and Mrs. Jack J. Marino ⊗

Mr. and Mrs. Ronald G. Robinson ⊗

**JUANITA ANDERSON**

Mrs. Tammy Chapman

**MAYER ARMBUST**

Sumerset Kare Bears

**TARYN AUTEN**

Ms. Mary Davis

**DANIELLE D. BABO**

Brian and Maureen Babo

Ms. Rachel Karbowski

**BILL BALL**

Mrs. Susan Ball

**KERRY K. BARDORF**

Don and Betty Hull

**CAROLYN J. BARRA**

David and Barbara Barra

**DOROTHY M. BARRY**

Kathleen and Justin Ruel

**HOPE C. BENNETT**

Lisa W. Wheeler, MT ⊗

**ARLENE BERRY**

Mrs. Phyllis Berry

Mr. Robert M. Boyd

Mr. Evan Erwin

**DOLORETTA S. BERUBE**

Mr. Roland J. Berube

**GLORIA BIESEMEYER**

Ms. Kami Biesemeyer ⊗

**CANDI C. BLEIFER**

Ms. Susan L. Salay

**GILBERT L. BLEW**

Ross and Karen Gibson

**WENDY S. BOCKHORST**

Mr. Jim Sherin

**JULIA BOGDAN-ROLLO**

Mr. and Mrs. Brian D’Andrea

Mr. Charlie Dubovici

Mr. Abner Figuereo

**RUTH BONAR**

PH Support Group: Iowa

**REBECCA JOY BUTLER**

Rick and Kathy Brown

Mr. Peter A. Comilla

The Cullen Family

Stanley and Pauline Cychowski

Mr. and Mrs. Lee M. Davis

Dr. P. Candace Deans

**Robert Rosene**

Chuck Sadler

Lynda O. Sawyers-Willis

Kimberly Scott

Michael P. Smith

Julian Willis

Joan Winters

Bernadine Young
Ms. Marcia A. Bako
Mr. Gregory Ball
Ms. Melissa A. Ball
Mrs. Tracy M. Ball
Ms. Bernadette Banas
Ms. Christine Banc
Mrs. Patricia Barbieri
Ms. Arcangela G. Barnicky
Ms. Meghan Baron
Mrs. Suzanne D. Bartolotta
Mrs. Rose Bartow
Mr. Michael Beck
Mrs. Debbie Beemiller
Mrs. Joyce Beesley
Mr. Bill Behrens
Mrs. Jeanette M. Bejot
Mrs. Linda Bengoc
Ms. Carne A. Biddle
Mrs. Regina Boone
Mrs. Ann BORDER
Ms. Jean C. Bourgeois
Ms. Kelly Braddock
Ms. Patricia M. Brent
Ms. Sharon Brodsky
Mr. Andrew Brown
Ms. Elaine Brown
Mr. Jon Buchner
Mrs. Mary Anne Burya
Ms. Marina Cabrall
Mr. and Mrs. Michael Caffrey
Ms. Sheila Campbell
Ms. Maria M. Campbell
Ms. Maureen Campbell
Ms. Barbara A. Carney
Mr. Jack Carroll
Mrs. Christine Carroll
Ms. Mary Beth Carter
Mrs. Jodi R. Caruso
Mrs. Mary Jo Cassese
Ms. Andrea Sein
Mrs. Marge Centa
Ms. Heidi L. Cerbin
Ms. Charlotte Cervella
Mr. William R. Cervenik
Mr. Patrick Cervenik
Mrs. Mary Chinchar
Mrs. Dawn Marie Chinchar
Mr. Douglas W. Chinchar
The Cindric Family
Ms. Kelly Clark
Ms. and Mr. Vickie Clark
Mr. Kevin Clarke
Mr. Jeff Clarke
Mrs. Melissa Clarke-Godina
Mrs. Barbara A. Clausing
Mr. Bob Clifford
Mrs. Sharon L. Cogar
Collinwood Memories Jr. Club
Mr. Dan Compton
Mrs. Christine M. Conway
Mrs. Polly E. Cusco
Ms. Melodie Cool
Mrs. Katie Corbett
Mrs. Lynda Corbett
Mrs. Shelley A. Cosmo
Mrs. Kristen Coyne
Mrs. Helma U. Crenan
Ms. Laura C. Crotty
Ms. Julie Dacar
Ms. Mary Dadaian
Mr. Matthew Dane
Mrs. Emily Dacicov
Ms. Michelle Davis
Mrs. Yvon Debelaak
Ms. Rena Deife
Dr. Barbara Dennis
Ms. Maureen Devito
Ms. Rita Diana
Ms. Kristina Diana
Mr. Mark Dicker
Mrs. Roberta Dieringer
Mrs. Antonina Digulis
Ms. Megan Disch
Miss Julia Dolce
Ms. Mary Jo Doyle
Mrs. Mary Dolsen
Mrs. Kristi Draper
Ms. Melanie Duffy
Mrs. Patty Dunmire
Mrs. Kate Eppich
Euclid Firefighters Local 337
Mrs. Annemarie Finch
Miss Sarah Finch
Ms. Elizabeth Fidnura
Mrs. Lisa A. Flachbart
Mrs. Kathy Fleck
Mr. Jim Forbes
Ms. Amy Forkins
Ms. Kristen Fortuna
Mr. Chris Foster
Mrs. Judy Freedman
Mr. Terry L. Freeman
Mrs. Bonnie L. Friedrich
Mrs. Tamara M. Fulksan
Mrs. Pamela Fynes
Ms. Dorothy F. Gaebelein
Mrs. Karen M. Gainford
Mr. Robert F. Gambatase, Jr.
Mr. Lee Gardella
Mrs. Elizabeth Garin
Mr. John Geisman
Mrs. Mary E. Geosano
Ms. Laura German
Dr. Cynthia Ghirman
Ms. Elizabeth Gilan
Gilead Sciences, Inc.
Ms. Sylvia P. Giebe
Ms. Beth Godina
Mr. Robert A. Godina
Mr. Vince Godina
Mr. Mark Godina
Mr. Vincent Godina
Mrs. Kathleen A. Gonakis
Ms. Angela Gowdy
Mrs. Kathy Grabowski
Mr. and Mrs. Ted Grabowski
Mr. David Grady
Mrs. Barbara J. Greeran
Mrs. Karen Greenway
Ms. Margaret Gretz
Mrs. Karen M. Greulich
Ms. Evonne Gundic
Mrs. Jean Hadney
Mrs. Mary A. Hadney
Mrs. Lauren E. Hadney
Ms. Lisa Hahn
Mr. Paul A. Hale
Mrs. Elizabeth Haller
Mrs. Susan M. Hamilton
Col. Thomas E. Hanlon, Ret.
Ms. Therese Hanson
Mrs. Dawn Hartman
Mr. George Hawk
Mr. Erik Hellier
Ms. Sharon Hensel
Mrs. Laura Hoenbaugh
Mrs. Catherine C. Hlavka
Ms. Laura Hoag
Mrs. Erin C. Hoffman
Mr. Matt Horton
Mr. Robert Hostetler
Ms. Julie Howe
Mrs. Somier Hoy
Mrs. Doris A. Hug
Ms. Debra A. Hula
Ms. Tanya Humphries
Mrs. Christina ice
Mrs. Kathleen O. Jandrey
Ms. Colleen Jasinski
Ms. Dianne L. Jazdyzk
Ms. Jennifer Jesberger
Mrs. Opal D. Johnson
Mrs. Deborah Johnson
Mr. Jeffery Jones
Mrs. Kris Kalinick
Mr. Patrick Kander
Ms. Marcy Kane
Mrs. Diane Kane
Mr. James Kasper
Mrs. Maria H. Kasper
Mrs. Diane L. Kasper
Ms. Cherie Kau
Mrs. Michelle Kavulich
Mr. Grant Keating
Mrs. Kathleen M. Keaveney
Ms. Diane Keanen
Mrs. Carol Keller
Mrs. Betsy Kennedy
Mrs. Deborah A. Kersman
Ms. Karen Kilkenny
Mr. Matthew King
Ms. Liana Kinnal
Mrs. Trisha Kirchner
Ms. Jill Klemm
Ms. Claudia Koler
Ms. Katherine M. Komar
Mr. Michael T. Korth
Mrs. Kabara Korth Praskavich
Ms. Lisa A. Krakowski
Mr. Craig Krejci
Ms. Gloria J. Krob
Mr. Slavko Kucinich
Mrs. Anne M. Kumer
Mrs. Lisa Kuta
Ms. Bridgette A. Lang
Ms. Lynne Lang
Miss Sara Lanzola
Miss Emily Lanzola
Mrs. Nancy L. Lanzola
Margaret and David Lanzola
Ms. Debbie Larch
Larmco Windows
Ms. Mia Laureinzo
Mr. Mario Lasch
Law Office of Joseph Raymond Skinka, Esq.
Ms. Melissa Lear
Mrs. Justine M. Leinberger
Mrs. Jennifer A. Leyrer
Mrs. Joyce Ann Leyer
Ms. Misty Lichvar
Mrs. Maureen Lippert
Mr. Paul Lonsway
Mr. Louis Loparo
Loretto Development Co., Ltd.
Ms. Linda Lupton
Ms. Kelly MacDonald-Tomaselli
Mrs. Ruby M. Macekko
Ms. Laura Mack
Ms. Melinda M. Madej
Mrs. Dina Magruder
Mr. Marley Magruder
Ms. Christine Mahaffey
Mrs. Debra Malinowski
Mr. Marc Malinowski
Mrs. Kathleen Manganelia
Mr. John Marinelli
Mrs. Clara Marra
Mr. Keith W. Martinet
Mrs. Cyndi Martony
Ms. Sheri Martz
Mr. Brian Mathews
Miss Maggie Maurer
Mrs. Holly K. Maurer
Mrs. Denise McBee
Mrs. Tamara McCarty
Mrs. Debra McClave
McCormack Family Chiropractic, Inc.
Mr. Donald McCune
Mrs. Patricia E. McDonough
Ms. April McFarland
Miss Nellie McHugh
Ms. Patricia McHugh
Ms. Angela K. McKeen
Mr. Mark E. McManus
Mr. Patrick McMullen
Mrs. Emer M. McNamara
Ms. Becky Meduetz
Ms. Nancy L. Meier
Mrs. Denise N. Merkulof
Ms. Stephanie M. Meyers
Ms. Susan Miller
Mr. Jeff Miozzi
Mr. Brock Missimen
Mrs. Shirley Mooney
Mr. Jeff Mooney
Ms. Loretta Moore
Ms. Marge Moore
Ms. Missy Moore
Mrs. Stacy A. Moormeier
Mr. Perry Morehouse
Ms. Melanie Moyer
Mr. John J. Murphy
Mrs. Kelly A. Murphy
Mrs. Jean Murphy
Ms. Cynthia Murray
Mr. John Murzynski
Ms. Betty Murzynski
Mr. Michael Nadoski
Mrs. Monica Nardy
Ms. Linda Nardy
Mr. Martin J. Norsic
Mr. Joe Nosan
Ms. Cheryl A. Novak
Ms. Lynn Novak
Ms. Debbie Nowalony
Mr. Charles J. Nusbaum
Mrs. Samantha O’Connell
Mrs. Mary Kay O’Donnell
Ms. D. Oliver
Mrs. Barb Ottman
The Pampered Chef
Mr. Mike Paoloni
Papp's Body Shop, Inc.
Mr. Paul Pastilong
Ms. Sandra Payne
Chris Peer
Mr. James M. Pehotsky
Mr. Bob Penny
Mrs. Nancy P. Piro
Ms. Lynn Phillips
Mr. Daniel Pike
Mr. David E. Ploenzke
Ms. Johnna Port
Mrs. Patricia A. Posey
Mrs. Sandra L. Post

www.PHAssociation.org
PATHLIGHT SUMMER 2011
44
Ms. Sue A. Sutkus
Ms. Geraldine Sustarsic
Mr. Tony Sustarsic
Mrs. Donna M. Sudar
Ms. Judy Streller
Mr. Larry Stout
Mrs. Karen Sudbury
Ms. Kathleen M. Sullivan
Mr. Tony Sustarsic
Ms. Geraldine Sustarsic
Ms. Sue A. Sutkus
Mr. Vince Sztul
Ms. Kristen Thomas
Mrs. Penny Marie Thomas
Mrs. Deborah Thuma
Tim Nice MD, Inc.
Today's Lifestyle Construction, Inc.
Ms. Lisa Tomaselli
Mrs. Dawn M. Toth
Ms. Kimberly Tramsak
Ms. Lisa Marie Trebec
Mr. Philip W. Troke
Mr. Bob Troop
Mrs. Nancy J. Trost
Ms. Angela Tucci
Mrs. Sharon A. Turk
Mrs. Tami K. Turner
Dr. Geoffrey Turoff
Mrs. Pamela Turows
United Towing Services Inc.
UPS Staff
Ms. Corie Van Korn gut
Ms. Jane Van Valkenburgh
Mrs. Michele N. VanHimbergen
Mr. Thomas S. Verdi
Mr. Frank Villanti
Mrs. Cheryl L. Vitelli
Mr. David Vrabel
Mr. David Wachhaus
Mrs. Debra A. Wachtcher
McKenna Walker
Mrs. Stacy L. Walsh
Ms. Therese M. Webb
Ms. Marilyn L. Werner
Mrs. Emily Westbrook
Mrs. Kelly M. Wills
Ms. Sarajane Wilson
Mrs. Jamie Wilson
Mr. Chancel Wilson
Mr. Tony Winborn
Mrs. Karen Wolf
Mr. Kirk A. Wolf
Mr. Steve Wrenn
Ms. Joyce A. Wright
Mrs. Laura Yama
Ms. Rhonda Yaxley
Mrs. Julia Ann M. Yoe
Mrs. Alison M. Zahler
Ms. Rose Zeitz
Dr. John Zielinski
Mrs. Carrie A. Zupanich
Mrs. Ninette R. Zuzek
Mrs. Carrie A. Zupanich
Mrs. Ninette R. Zuzek
AURORA ZONEGA
Leyden High Schools
BARBARA B. GOODIN
Mr. Kevin Benson
Ms. Pauline A. Blum
Dearborn County Hospital
Ruth Ann, Jim and Judy Ebbers
Carol and Urban Ebert
Carl and Vicki Goodin
Mrs. Mary Ann Gordon
Mr. and Mrs. Embry Grimes
Ms. June Heinzelman
Marge and Ray Lehman
Mr. and Mrs. Richard T. Mailn
Ms. Mary Jane Maxwell
Mr. and Mrs. Sharon A. O'Rourke
Paul and Cherie Riesterberg
William and Joan Gail Snider
Ms. Melissa K. Weidmer
JAMES M. GORE
Ms. Delia Misselbrook
Mr. Vincent Sztul
Ms. Kristen Thomas
Mrs. Penny Marie Thomas
Mrs. Deborah Thuma
Tim Nice MD, Inc.
Today's Lifestyle Construction, Inc.
Ms. Lisa Tomaselli
Mrs. Dawn M. Toth
Ms. Kimberly Tramsak
Ms. Lisa Marie Trebec
Mr. Philip W. Troke
Mr. Bob Troop
Mrs. Nancy J. Trost
Ms. Angela Tucci
Mrs. Sharon A. Turk
Mrs. Tami K. Turner
Dr. Geoffrey Turoff
Mrs. Pamela Turows
United Towing Services Inc.
UPS Staff
Ms. Corie Van Korn gut
Ms. Jane Van Valkenburgh
Mrs. Michele N. VanHimbergen
Mr. Thomas S. Verdi
Mr. Frank Villanti
Mrs. Cheryl L. Vitelli
Mr. David Vrabel
Mr. David Wachhaus
Mrs. Debra A. Wachtcher
McKenna Walker
Mrs. Stacy L. Walsh
Ms. Therese M. Webb
Ms. Marilyn L. Werner
Mrs. Emily Westbrook
Mrs. Kelly M. Wills
Ms. Sarajane Wilson
Mrs. Jamie Wilson
Mr. Chancel Wilson
Mr. Tony Winborn
Mrs. Karen Wolf
Mr. Kirk A. Wolf
Mr. Steve Wrenn
Ms. Joyce A. Wright
Mrs. Laura Yama
Ms. Rhonda Yaxley
Mrs. Julia Ann M. Yoe
Mrs. Alison M. Zahler
Ms. Rose Zeitz
Dr. John Zielinski
Mrs. Carrie A. Zupanich
Mrs. Ninette R. Zuzek
AURORA ZONEGA
Leyden High Schools
BARBARA B. GOODIN
Mr. Kevin Benson
Ms. Pauline A. Blum
Dearborn County Hospital
Ruth Ann, Jim and Judy Ebbers
Carol and Urban Ebert
Carl and Vicki Goodin
Mrs. Mary Ann Gordon
Mr. and Mrs. Embry Grimes
Ms. June Heinzelman
Marge and Ray Lehman
Mr. and Mrs. Richard T. Mailn
Ms. Mary Jane Maxwell
Mr. and Mrs. Sharon A. O'Rourke
Paul and Cherie Riesterberg
William and Joan Gail Snider
Ms. Melissa K. Weidmer
JAMES M. GORE
Ms. Delia Misselbrook
Ms. Edith Ben-Horin
Ms. Janelle Beitz
Mrs. Delia Misselbrook
PATHLIGHT SUMMER 2011  Patient-to-Patient Support Line: 1-800-748-7274
Mrs. Mary Lou Light
Mr. and Mrs. Don Mielke
Mr. and Mrs. Charles Sadler
Mrs. Brenda Thomason
Jerry and Janet Vandebergh
LYNDA O. SAWYERS-WILLIUS
Mrs. Kim Adams
Mr. Dominic Agepog
Mrs. Hilarie Boone
Mrs. Beverly Clevenger
Mrs. Tina DeHaven
Mr. and Mrs. James Dennis
Ms. Malinda Kroskie
Mr. Peter W. O’Hara
Mr. Larry L. Willis
Mr. and Mrs. Robert F. Zydelis
TIFFANY A. SCALONE
Andrew and Stella Astromonte
Pam and Jimi Colon
ROY K. SCHARDIN
Ms. Helen L. Schardin
MARY B. SCHUMACHER
PH Support Group: Iowa
BARBARA L. SCOTT
Ms. Wilma L. Scott
KIMBERLY A. SCOTT
Ms. Diane P. Allemann-Stevens
Ms. Linda Baker
Community Bank of Santa Maria
Mrs. Carol Cossa
Dennis Bethel & Associates, Inc.
Ms. Julie DeSantis
Dian Ward Diian, LLC
Ms. Sandra M. Dunne
Ms. Anne Gagne
Mr. and Mrs. Herbert Gerfen
Ms. Sherrie Goodrich
Mr. Dusatan Johnson
Mr. Jerry Meyer
Bill and Judy Moffatt
E. W. Olson and J. R. Lynch
Santa Maria Valley Chamber of Commerce
Mr. Steven C. Scott
Mr. Robert W. W. Scott
Ms. Valerie Tesauro
Trojan Petroleum, Inc.
Mr. Jerry Williams
KIM SCOTT
Zorina Schutz, RN, MSN, CCRN
RAMONA SEARCY
Ms. Carol Jeanette Volkmann
KAROLYN SEBASTIAN
Mrs. Patricia J. Sebastian
KEITH SEBASTIAN
Mrs. Patricia J. Sebastian
JOHN SEBASTIAN
Mrs. Patricia J. Sebastian
KEN SEBASTIAN
Mrs. Patricia J. Sebastian
KATHY SEBASTIAN
Mrs. Patricia J. Sebastian
KELLY SEIBERT
Dr. and Mrs. Mitchell Koppelman
Minerals Technologies
Ronald and Mary Lou Zach
DANIEL M. SHERIDAN
Ms. Jean D. Pitcher
Ms. Jean Sheridan
HERB SHERNOFF
Conn and Sue Epstein
MARGENE SMITH
The Honorable Jeannie DiMauro
MICHAEL P. SMITH
Ms. Mary J. Murray
AMY C. STAMP
Mrs. Nancy Bair, RN, MSN, CNS
Lloyd and Patricia Kibbe
Ms. Merle Reeseman
BONNIE D. STEADMAN
Mr. Robert W. Steadman
MARY T. STEELE
Ms. Lori Dow
John J. Greene, Esq.
JOYCE A. STEVENS
Mr. Vaughn M. Stevens
Ms. Daryl B. Whitt
NEDRA A. STRAWN
PH Support Group: Iowa
ANGELIQUE STUBBS
Mrs. Cheryl Eagy
JOY C. SULLIVAN
Ms. Remiliza Cristobal
LARANE TAY
Ms. Linda M. Pierce
NICHOLAS TEDESCO
Mrs. M. Clara Tedesco
PATRICIA H. TERRY
Mr. James K. Terry
ARNOLD J. TIMM
Mr. and Mrs. Arnold H. Timm
SARAH TOWNSEND
Ms. Leslie Polsa
ALEXA TUNITIS
Mr. and Mrs. Daniel R. Wheeler
JOSEPH TYMCZYSZYN
William and Cheryl Tymczyszyn
SOPHIA VOLINO
Mrs. Kimberly A. Currie
Ms. Brenda M. Kolibas
BARBARA WALLACE
Mrs. Dawn Evans
AMANDA WEBER
Mr. Anton Weber
CRISTIN LYNN WHITE
Bowling Green R-1 High School
Volleyball Team
ANNETTE B. WHITNEY
Ms. Katharina Fuller
Mrs. Joyce Gerlak
Ms. Sarah J. Randles
Mr. Douglas R. Whitney
SHAWN J. WIGGINS
Ed and Judy Simpson
SHIRLEY L. WILHITE
Mr. Raymond A. Wilhte
DELAISY WILLIAMS
Ms. Miroshala Allison
JULIAN WILLIS
Mrs. Annamaria Augustine
Mr. Kevin Brant
Mr. Marty Carey
Mr. Kurt A. Carlsson
Mr. Mike Stoveken
Mr. Richard J. Willis, Jr.
PATRICIA S. WILSON
Loris and Gary Sherman
JERRY WOJCIECHOWSKI
Mr. and Mrs. Paul Andersen
Mrs. Kellie Andersen
Ms. Kathleen M. Branigan
Ms. Kathy Carr
Mrs. Dianna Contino
Ms. Diane Davis
Ms. Colette M. Eaglehouse
Joanne and Lynn Eichhorster
Ms. Judy A. Foster
Ms. Regina Friedrich
Mr. and Mrs. Brian F. Garland
Jim and Karen Havlena
Christina and Christopher Hawtrey
Mr. Gerald Hegger
Hill House Products
Mrs. Asako U. Iagwa
Mrs. Patricia Jabuka
Mr. and Mrs. Jerel K. Jackson
Mr. and Mrs. William L. Peirce
Mr. and Mrs. Sheldon T. Kawahara
Mr. Daniel Kelley
Ms. Linda Kimble
Ms. Karla Kriz
Mrs. Jill M. Lee
Mr. and Mrs. Philip E. Lewis
Michael and Bonnie McGoona
Ms. Sandra Minich
Mr. Richard Moyer
Ms. Martha L. Mulkiewicz
Mr. Robert Munson
Mr. and Mrs. Richard C. Pepin
Mrs. Amala Peruman
Mrs. Gail J. Rucker
Ms. Susan L. Salay
Mr. Gerardo R. Santos
Mr. and Mrs. Edward V. Shipley, Jr.
Ms. Kathryn A. Skjei
Mrs. Alice L. Smith
Mr. John Stonebarger
Tomkinson & Associates, Inc.
Ms. Carrie D. Toso
Ms. Betty Lou Wojciechowski
MICHAEL WOJCIECHOWSKI
Mr. and Mrs. Paul Andersen
Mrs. Kellie Andersen
Ms. Kathleen M. Branigan
Mrs. Alice L. Smith
Mr. and Mrs. Jerel K. Jackson
Mr. and Mrs. William L. Peirce
Mr. and Mrs. Sheldon T. Kawahara
Mr. Daniel Kelley
Ms. Linda Kimble
Ms. Karla Kriz
Mrs. Jill M. Lee
Mr. and Mrs. Philip E. Lewis
Michael and Bonnie McGoona
Ms. Sandra Minich
Mr. Richard Moyer
Ms. Martha L. Mulkiewicz
Mr. Robert Munson
Mr. and Mrs. Richard C. Pepin
Mrs. Amala Peruman
Mrs. Gail J. Rucker
Ms. Susan L. Salay
Mr. Gerardo R. Santos
Mr. and Mrs. Edward V. Shipley, Jr.
Ms. Kathryn A. Skjei
Mrs. Alice L. Smith
Mr. John Stonebarger
Tomkinson & Associates, Inc.
Ms. Carrie D. Toso
Ms. Betty Lou Wojciechowski
MATTHEW WOJCIECHOWSKI
Mr. and Mrs. Paul Andersen
Mrs. Kellie Andersen
Ms. Kathleen M. Branigan
Mr. and Mrs. Jerel K. Jackson
Mrs. Dianna Contino
Ms. Diane Davis
Mrs. Colette M. Eaglehouse
Joanne and Lynn Eichhorster
Mrs. Trudy A. Foster
Ms. Regina Friedrich
Mr. and Mrs. Brian F. Garland
Jim and Karen Havlena
Christina and Christopher Hawtrey
Mr. Gerald Hegger
Hill House Products
Mr. Asako U. Iagwa
Mrs. Patricia Jabuka
Mr. and Mrs. Jerel K. Jackson
Mr. and Mrs. William L. Peirce
Mr. and Mrs. Sheldon T. Kawahara
Mr. Daniel Kelley
Ms. Linda Kimble
Ms. Karla Kriz
Mrs. Jill M. Lee
Mr. and Mrs. Philip E. Lewis
Michael and Bonnie McGoona
Ms. Sandra Minich
Mr. Richard Moyer
Ms. Martha L. Mulkiewicz
Mr. Robert Munson
Mr. and Mrs. Richard C. Pepin
Mrs. Amala Peruman
Mrs. Gail J. Rucker
Ms. Susan L. Salay
Mr. Gerardo R. Santos
Mr. and Mrs. Edward V. Shipley, Jr.
Ms. Kathryn A. Skjei
Mrs. Alice L. Smith
Mr. John Stonebarger
Tomkinson & Associates, Inc.
Ms. Carrie D. Toso
Ms. Betty Lou Wojciechowski
SHARREN YAMRON
Ms. Carolyn C. Batz
Mr. Michael K. Feeney
Ms. Kathleen Harrison
Mr. Nat Hunter
Ms. Laurene Kane
Ms. Marla Presley
Mr. David Robertson
Mr. Gary T. Yamron
Mr. Sam Yamron
Mr. Lawrence Yamron
BERNADINE YOUNG
Ms. Antoinette V. Andolfatto
Mr. and Mrs. John Brunnabend
Mrs. Sharon K. Napolitano
Mr. and Mrs. Joe Colon
Mr. Adam C. Crahall
Ms. Kathleen M. Donaghy
Mrs. Karen J. Gehrett
Ms. Dorothy Howe
Mrs. Jean Knorr
Ms. Patricia McHugh
Mrs. Bonnie Mitchell
Mrs. Marilyn Peterson
Mrs. Carol Pionola
William and Kathleen Scheufeke
White Tail Ski Patrol
Ms. Jean P. Young
Ms. Alicia Melina Bridgewater
Mrs. Loretha Brethour
Ms. Linda Brauchler
Ms. Dorothy E. Bradley
Daniel and Lowanda Vanessa
Ms. Dawn H. Boyle
Ms. Vicky Bowlby
Mr. Ray Bowers
Ms. Bonita L. Boutin
Joan Bonnell, RN
Ms. Antoinette Boener
Blue Agave
Ms. Anna Bloch
Mrs. Mary L. Blevins
Mr. and Mrs. Richard D. Blesener
Col. and Mrs. Benjamin H. Boynton
Mrs. Andrea Banworth
Mr. and Mrs. Mark D. Banny
Ms. Antoinette Boener
Mr. and Mrs. Robert L. Benfield
Mrs. Judy Benway
Mr. and Mrs. James L. Benfield
Mr. and Mrs. John A. Benfield
Ms. Patricia A. Black
BJ's Wholesale Club
Ms. Renee' A. Bissmeyer
Mrs. Carol A. Blank
Mr. Jack Clemens
Mr. Jack Clemens
Ms. Susan M. Ciupak
Ciccione's
Ms. Mary C. Ciupak
Ms. Robin Clark
Mr. and Mrs. Jack Clemens
Mr. Jack Clemens
Mrs. Constance Clemmons
Ms. Anita Clemmons
Cleveland Metroparks
Ms. Valerie Cieck
Ms. Mary L. Clifford
Mrs. Carol K. Clullee
Ms. Allison Cohen
Mrs. Rosemary J. Cole
Mrs. Ardith Coleman
Mrs. Martha Sue Collins
William and Denise Coates
Columbia Presbyterian Medical Center
Mr. and Mrs. David H. Combs
Mrs. Roberta A. Conant
Ms. Carol J. Condé
Mr. and Mrs. Hugh H. Connett
Mrs. Tracy Connolly
Ms. Gerilyn A. Connors, RRT
Ms. Beverly J. Conte
Mr. Robert Converse
Ms. Patty Connetz
Mrs. Marlene A. Cook, RN
Mr. Andrew Cooksey
Yolanda A. Cordon, MD
Mrs. Kimberly Corson
Mr. Danny Courtz
Ms. Mary Coso
Mrs. Elizabeth Costa
Mr. Daniel Costello
Mrs. Elizabeth A. Coughlin
George and Vonda Coulier
Mr. Jeff Counseller
Miss Isabelle Coutlier
Bart Cox
Ms. Debbie Cox
Mr. Richard F. Cox
Ms. Shirley J. Craig
Mr. Russ Crall
Mr. M. Scott Creecy
Ms. Mary Anne Cremin
Ms. Evelyn Crespo
Mr. James Cronin
Ms. Kaye Cross
Miss Charlotte E. Cross-Folston
Crossroad Design
Mrs. Karen Crow
Ms. Lisa M. Crowley
Ms. Madlyn A. Cullen
Mrs. Helen Culp
Ms. Sandra L. Culp
CuraScript
Mr. Ronald Curtiss
Ms. Kathleen Czachor
Mr. Paul Czysz
Ms. Maryann Dahmen
Daletown Country
Mrs. Dianne M. Daly
Mrs. Minh-Tam Darn
Mrs. Elaine Daniels
Ms. Jeanette Danielson
Mrs. Joan M. Danley
Noelle Danos
Janice Davenport
Mrs. Claire Davila
Ms. Diane Davis
Mr. Duane Davis
Ms. Emily E. Davis
Mr. Joseph Davis
Ms. Kim Davis
Mr. Larry Davis
Mrs. Nancy Lee Davis
Ms. Penny Davis
Mrs. Debby Dawson-Crain
Mr. Timothy T. Day, Jr.
Mr. Deven J. Anthony and Mrs. Teresita S. De Guzman
Ms. Joanne M. De Oliveira
Mr. Phillip J. Deebe
Mrs. Darlene M. Delgado
Mr. Charles R. Delp
Mrs. Marie E. DeRossi
Ms. Susan Demers
Dr. Edward Dempsey
Mr. Alfred Demnann
Mr. Jerry Demnam
Mrs. Therese B. Demnomme
Ms. Marguerite J. DePrado
Mr. Joel Deretchin
Ms. Marcia E. DeSerres
Detroit Auto Parts
Amy DeYoung, RRT
Mrs. Laura B. Dezubay
DGI Beverage, LLC
Mr. Charly Diaz
Mrs. Karen Diaz
Mr. Raul Diaz
Mrs. Elizabeth DiMarco
The Honorable Jeanne DiMauro
Mr. Michael Dinke
Discovery Place
Ms. Eta J. Distaffan
Miss Denise M. Dixon
Ms. Jennie Do
Ms. Myrna Dobbins
Dockside Seafood Restaurant
Mr. Gerald Dodson
Mr. and Mrs. John J. Doherty
Mrs. Ruth A. Dolan
Mrs. Betty L. Dombrowski
Ms. Patricia A. Donegan
Jerry and Susan Donsbach
Mrs. Caitlin Downs
Ms. Holly C. Doyle
Ms. Veronica Dragich
Mrs. Sylvia Drayton
Mrs. Jacobs, Lansung & Mishkin, PA
Ms. Patrick E.
Mr. Stephen Duffy
Mrs. Laciunda Dungan
Ms. Gloria E. Dunley
Ms. Pamela J. Dunn
Ms. Marilyn M. Duque
Mrs. Gabriel M. Duque
Mr. Thomas E. Duque
Mrs. Anna Grace Durst
Louise A. Durst, RN
Mr. Alex C. Dusek
Mr. Robert Dushek
Laurel Dunn, PharmD
Mr. and Mrs. John G. Dyott
Mrs. Cheryl Eady
Ms. Shirley G. Earnest
Ms. Linda Easley
Eatons Family Credit Union
Ms. Kathy Eberwein
Ms. Nancy Edmonds
Mr. Roy Eisenhandler
Ms. Helen K. Elchik
El Lilly and Company
Mr. Tom Elchik
Mr. and Mrs. Dan Ellington
Tony Singer and Mary Beth Enslin
Ms. Frances Enzone
Camm and Sue Epstein
Patrick and Maria Evans
Mr. Randel Evans
Mrs. Sue Evans
Mrs. Claudia Everette
Express Scripts, Inc.
Karen A. Fagan, MD
Mrs. Dana Falk
Mr. and Mrs. James W. Fallon, Sr.
Mr. and Mrs. Donald J. Fanzo
Mrs. Dorothy A. Fecteau
Ms. Frances C. Fee
John Feenstra, MD
Mrs. Hija E. Felix
Ms. Janet Ferr
Mr. Kenneth Fenton
Ms. Aurora Fernandez
Ms. Tiffany Fernandez
Mrs. Sue-Ellen Finelt
Ms. Christine J. Fini
Ms. Lisa M. Finlayson
Mr. and Mrs. Donald J. Finn
Ms. Alice P. Fioramonti
First Victoria
Mr. Daniel W. Firth
Mrs. Lois Fish
Mr. Harold Fisher
Flat Rock Play House
Mr. and Mrs. Donald J. Finn
Ms. Alice P. Fioramonti
First Victoria
PHA’S LEGACY OF HOPE SOCIETY

To honor those who have included PHA in their estate plans or whose legacies have been realized, PHA created the Legacy of Hope Society. PHA is pleased to recognize the following members.

Sandra Alt Awood  
Dauna Leigh Bauer*  
Sylvia Marie Becherer*  
Gloria G. Blodgett*  
Dorothy E. Bradley  
Roberta F. Browning* and Lee Broadent  
Rita and Bruce Brundage  
Jane P.* and Harold P. Cooper  
James F. Corbett*  
Lauru Hoyt D’Anna, DrPH  
Charles W. DeVier, III*  
Linda M. Feibel*  
Barbara Gamer  
Tammy* and Dean Hazen  
Mary and Carl Hicks  
Jacquelyn Holt  
Richard L. Horocks  
Terri L. Kopp*  
Gloria Lang*  
Thomas and Mary Jo Linnen

*deceased members

For more information on PHA’s legacy planning program, call Jillian at 301-565-3004 x767, email Giving@PHAssociation.org or visit www.PHAssociation.org/Give

ARE WE MISSING YOU?

Please update my mailing list information as follows:  
(Please print.)

☑ Mr.  ☐ Mrs.  ☐ Ms  ☐ Dr.  ☐ Miss
Name: __________________________
Business (if any): ____________________________________________________________
Address: _____________________________________________________________
City: _______________________________________________ State: _________________ Zip: ____________________

☐ Please check here if this is an address change.
Phone: __________________________ Fax: __________________________
Email: __________________________
I am a:  
☐ Patient  ☐ Caregiver  ☐ Parent of a child with PH  
☐ Medical professional (title and affiliation):

Mail or fax completed form to:  
Pulmonary Hypertension Association  
801 Roeder Road, Ste. 1000  
Silver Spring, MD 20910  
Fax: 301-565-3994

You may also submit a change of address online at www.PHAssociation.org/ContactUs

PHA STAFF

Rino Aldrighetti  
President  
Rino@PHAssociation.org

Adrienne Dem  
Senior Vice President  
Adrienne@PHAssociation.org

Candice Abate  
Vice President, Medical Services & Patient Education  
Candice@PHAssociation.org

Margaret Beardsworth  
Insurance Program Manager  
Margaret@PHAssociation.org

Emma Bonanomi  
Associate Director, Patient Outreach and Services  
Emma@PHAssociation.org

Dorothy Bradley  
Office Assistant

Amanda Butts  
Director, Office of the President  
Amanda@PHAssociation.org

Debbie Castro  
Director of Volunteer Services  
Debbie@PHAssociation.org

Micaela Cohen  
Associate Director of Medical Services  
Micaela@PHAssociation.org

Tracey Delaney  
Office Assistant  
Tracey@PHAssociation.org

Christine Dickler  
Associate Director, Publications Design  
Christine@PHAssociation.org

Sylvia Earley  
Communications & Development Coordinator  
Sylvia@PHAssociation.org

Meghan Finney  
Patient Education Program Associate  
Meghan@PHAssociation.org

Caitlin Flewellen  
Online Education Associate  
Caitlin@PHAssociation.org

Suzanne Flood  
Marketing & Communications Manager  
Suzanne@PHAssociation.org

Kathryn Frix  
Online Community Liaison  
Kathryn@PHAssociation.org

Diane Greenhalgh  
Director of Web Services  
Diane@PHAssociation.org

April Grimsley  
Administrative Assistant  
April@PHAssociation.org

Carsten Halley  
Meetings Planning Associate  
Carsten@PHAssociation.org

Patty Hunt  
Associate Director of Finance & HR  
PattyH@PHAssociation.org

Jennifer Kaminski  
Development Manager  
JenniferK@PHAssociation.org

Sophie Klein  
Volunteer Services Associate  
Sophie@PHAssociation.org

Arsène Koissy  
Database Manager  
Arsene@PHAssociation.org

Katie Krone  
Director of Advocacy and Awareness  
Katie@PHAssociation.org

Doreen Lucadamo  
Director of Meetings & Conference Planning  
Doreen@PHAssociation.org

Leslie Mahaney  
Special Events Associate  
Leslie@PHAssociation.org

Megan Mallory  
Associate Director, Publications, Pathfinder Editor  
Megan@PHAssociation.org

Jillian McCabe  
Associate Director of Development  
Jillian@PHAssociation.org

Jessica McKeen  
Associate Director, Special Events  
JessicaM@PHAssociation.org

Michal Rachlin  
Kerry Bardorf Family Support Program Associate  
Michal@PHAssociation.org

Jessica Ritter  
Office Operations and IT Manager  
Jessica@PHAssociation.org

Patty Scudder  
Director of Finance  
Patty@PHAssociation.org

Meghan Tammaro  
International Services Manager  
MeghanT@PHAssociation.org

Keisha Thomas  
Grassroots Campaigns Associate  
Keisha@PHAssociation.org

Rachel Wheat  
Allied Health Program Associate  
Rachel@PHAssociation.org

Elisabeth Williams  
Grassroots Campaigns Associate  
Elisabeth@PHAssociation.org

Please check here if this is an address change.

Mail or fax completed form to:  
Pulmonary Hypertension Association  
801 Roeder Road, Ste. 1000  
Silver Spring, MD 20910  
Fax: 301-565-3994

You may also submit a change of address online at www.PHAssociation.org/ContactUs

www.PHAssociation.org
PATHLIGHT SUMMER 2011

PATHLIGHT & PERSISTENT VOICES SUBMISSIONS

The Fall Issue deadline is July 31, 2011.

Pathlight is your publication. Tell us about your support group, recent event, phenomenal PHer or anything else you’d like to share. Let us know how you cope with PH, how you live and work every day. We’ll accept articles, quotes, photos, tributes, etc. for consideration in the newsletter. We also accept submissions of personal PH stories, pictures, poems and quotes for publication in the next issue of Persistent Voices. If you’re not comfortable writing your story — or if you just can’t find the time — contact us and we’ll interview you about it and write it for you. If you are interested in reporting for Pathlight or conducting interviews with other members of the community, let us know. Please contact us with your input and stories! Send submissions, with your phone number, to:

“Newsletter Submission” or “Newsletter Submission”
Print Services Department
Print@PHAssociation.org
Pulmonary Hypertension Association
801 Roeder Road, Ste. 1000
Silver Spring, MD 20910

Work submitted will be printed as space permits. Please let us know if you would like anything returned. PHA cannot be held responsible for any materials lost.

BOARD OF TRUSTEES

Laura D’Anna, DrPH, Chair
Vallarie V. McLaughlin, MD, Chair-Elect
Sally Maddox, Secretary
Roger Towle, Treasurer
Carl Hicks, Immediate Past Chair

Robyn J. Barst, MD
Colleen Brunetti
Linda Carr
Richard Channick, MD, SLC Representative
Louise Durst, RN, PH Professional Network Representative
C. Gregory Elliott, MD
John Hess
Dunbar Ivy, MD
Mark Jeter
Tory Lahnston
Michael D. McGoon, MD
Rita Orth, RN
Cindy Pickles, RN
Diane Ramirez
Harry R. Rozakis
Traci Stewart, RN, PH Professional Network Representative
Jack Stibbs
Steve Van Wormer
Rev. Stephen White, PhD

Emeritus
Dorothy Olson
Harry Olson
Jerry Paton
Pat Paton, RN
Edwin Simpson
Judith Simpson, RN, EDS

Ex Officio
Rino Aldrighetti

PATIENT & PERSISTENT VOICES

Megan Mallory, Editor
Michael D. McGoon, MD, Medical Co-Editor
Karen A. Fagan, MD, Medical Co-Editor
Camille Frede, Youth Phenomenal Youth Editor
Nancy Frede, Parent Phenomenal Youth Editor
Amanda Martin, Volunteer Copyeditor
Edward Freundl, Volunteer Copyeditor
Jodi Palmer, Volunteer Copyeditor

PATHLIGHT & PERSISTENT VOICES

PHA thanks the Pathlight Roundtable volunteers for their guidance and contributions to this issue of Pathlight.

Shirley Craig, General Review
Robert Tash, Volunteer Services
Raye Bohn, Advocacy and Awareness
Jessica Lazar, P.A., Medical Services

PATHLIGHT & PERSISTENT VOICES

PATIENT & PERSISTENT VOICES

Megan Mallory, Editor
Michael D. McGoon, MD, Medical Co-Editor
Karen A. Fagan, MD, Medical Co-Editor
Camille Frede, Youth Phenomenal Youth Editor
Nancy Frede, Parent Phenomenal Youth Editor
Amanda Martin, Volunteer Copyeditor
Edward Freundl, Volunteer Copyeditor
Jodi Palmer, Volunteer Copyeditor

PATHLIGHT & PERSISTENT VOICES

PHA thanks the Pathlight Roundtable volunteers for their guidance and contributions to this issue of Pathlight.

Shirley Craig, General Review
Robert Tash, Volunteer Services
Raye Bohn, Advocacy and Awareness
Jessica Lazar, P.A., Medical Services

PATHLIGHT SUMMER 2011

Patient-to-Patient Support Line: 1-800-748-7274
What is PHA?

PHA has grown a lot over the years! Whether you're new to our community — or have been with us for some time — you might really appreciate our handy new 12-page booklet. “What Is PHA?” describes PHA’s programs and services in the areas of support, education, ways to get involved, research, medical professional advancement and more. Request your copy today! Order online from PHA’s store (Free Materials) or call 301-565-3004 x0.

Don’t want to wait three months for more news from PHA?

Sign up for PHANews, PHA’s biweekly e-newsletter, and receive news from the PH community every other week in your Inbox!

www.PHAssociation.org/PHANews